

## **Chapter 2 – Relationship and Context of ACDs to Boomers**

The purpose of this chapter is to analyse the historical, legal, ethical, psychological and societal factors that have underpinned the use of ACDs. Following analysis of these factors, the relationship of the context of ACDs to the Boomer generation will be described. Exploring the relationship of ACDs to Boomers required consideration of the contexts in which both have arisen including the influence of increasing longevity (Schneiderman, 2011; ABS, 2010b, 2009; Camhi et al. 2009; WHO, 2009; Elliot, 2008; Clark, 2002). The impact longevity is having on healthcare resource provision has generated an increasing volume of literature at local, national and international levels and has been acknowledged within policy-making circles as a future concern (PC, 2011; WHO, 2009).

The current literature described the issues at stake, however it did not provide any substantial evidence that diminishing healthcare resource provision may be influencing individual Boomer ACD decision-making. Instead, the literature has focused mainly on the legal and ethical aspects of these instruments; such as which instruments apply to different types of decision-making and which ethical principles should take precedence in decision-making (Kerridge, et al. 2009b; SAG, 2008b, c; Collins, et al. 2006; Nuffield Council on Bioethics (NCB), 2007; NSWG, 2004; The SUPPORT Investigators, 1995). Actual effectiveness of these instruments for supporting personal autonomy in healthcare was acknowledged as being under-researched (Bravo, et al. 2008; Jezewski, et al. 2007). Though effectiveness of these instruments for preserving autonomy in decision-making remained unclear, nonetheless the literature showed support for their continued use throughout the democratic countries where they have been legislated. Understanding why this support has continued has necessitated understanding the historical development of these instruments and their reason for existence. The following section describes this historical development.

### ***Historical Development of ACDs***

The advent of specific instructions about future healthcare and welfare management for the individual developed in democratic societies in the late 1960s and 1970s in response to increasing community expectations of personal liberty and freedom to determine one's choices in life, including the freedom to make decisions about one's health and wellbeing even after capacity for decision-making was gone (Kerridge, et al. 2009b; Wilkinson, et al. 2007; Brown, 2006). The literature provided examples of forms that promoted personal freedom, including, but not limited to do-not-resuscitate forms (DNR) and organ donor cards which enable a person to determine actions to be taken with their body after death (Brown & Jarrad, 2005b). Do-not-resuscitate forms were one of the first versions of ACD developed and formalised a person's express wishes about what recovery actions they would consent to when unable to personally consent or refuse medical interventions (Hillman, 2010; Wilkinson et al. 2007). Advance care directives in the form of DNRs are an expression of informed consent that was legislated in SA through The Consent to Medical Treatment and Palliative Care Act (1995).

As ACDs such as DNR orders were developed, Boomers who were adults at this time became increasingly aware that they might be required to participate in healthcare and welfare decision-making both for themselves and for others. This healthcare and welfare decision-making included the choice of whether or not to accede to medical interventions that prolonged theirs and others' lives with compromised QOL (Teno, et al. 2007; CARES, 1997; The SUPPORT Investigators, 1995). Examples of the type of medical interventions applicable to this decision-making included cardiopulmonary resuscitation (CPR) (which is countered by a DNR order) as well as artificial nutrition and hydration (ANH) and Non-invasive or Invasive Positive Pressure Ventilation (NIPPV) (The Australian Lung Foundation, 2011; Hillman, 2010; Kuo, et al. 2009; Rubin, 2007; Gillick, 2006).

Boomers would have observed as they matured that these highly advanced and invasive medical technologies generated complicated decision-making when expected death was significantly delayed. Compounding this decision-making was the creation of a public perception that these medical technologies were a normal part of treatment programs rather than a means of extending life until trauma-induced states subsided and the potentiality of life-

saving treatment could be assessed (Hillman, 2010; Lopez, et al. 2010; Clements, 2009; Martin & Roberto, 2006). As public understanding evolved of the trade-offs required with this decision-making, ethical debates by religious, medical and voluntary euthanasia groups about longevity, suffering, medical futility and the right to die ensued (Schneiderman, 2011; South Australian Voluntary Euthanasia Society (SAVES), 2010; Thrane, 2010; Tucker, 2009; Lynch, et al. 2008; Australian Medical Association (AMA), 2007). These debates produced a demand by members of the Boomer generation to preserve personal autonomy in future medical decision-making through legislation which acknowledged the right of the individual to engage in future care planning. The next section discusses the legislative development of the ACD instruments developed as a result of these historical debates.

### ***Legal Development of ACDs***

The seminal event often referred to in the literature as the catalyst for development of ACDs was the case in the New Jersey Supreme Court (1976) United State of America (USA), of Karen Ann Quinlan (*Re Quinlan (1976) 70 NJ 10, New Jersey Supreme Court*). Ms Quinlan, herself a Boomer, was hospitalised in a persistent vegetative state after a drug overdose. The quality of life her family felt she experienced at that time was such that her family deemed her life no longer worth living. Conflict arose between family and hospital personnel when the hospital refused to cease Ms Quinlan's life support at the family's request. The public debate that ensued emphasised to Boomers that medicine not only had the ability to extend life but also to extend it without family consent and without consideration of the quality of life left to the patient (Stanley, 1989). To counteract the increasing dominance of medical interventions over quality of life decisions, Boomers began to realise that if their wishes were not expressed in advance and the expression of these wishes legitimated, it might require a court order to ensure choice and control not only in their care but also the continuation of their life and quality of their death.

Subsequent cases like those of Cruzan (*Re Cruzan (1990) 261, 497, Missouri Department of Health, United States Supreme Court*) and Schiavo (*Re Schiavo (2005), 648897, Florida District Circuit Court*) in the USA also

featured Supreme Court intervention to resolve conflict between healthcare providers and family decision-making. All of these cases reinforced the perception and need for ACDs, especially when multiple parties argued for or against the continuation of life without clear prior instruction of what the person would have wanted under the circumstances. The cases of Quinlan, Cruzan and Schiavo were often referred to in the literature as setting the precedent for protecting personal autonomy in healthcare decision-making through ACDs (Wilkinson, et al. 2007). In the USA this demand for personal autonomy in medical treatment decision-making culminated in the development of the Patient Self Determination Act (PSDA, 1990). This Act promoted and preserved the right to use ACDs for advance care decision-making in that country. Since its inception, the PSDA (1990) has also served as the basis for subsequent legislation in other countries such as Australia, to preserve the right of an individual to not only make decisions about future healthcare treatments but also nominate guardians to act on their behalf when they are not able, through incapacity, to make decisions themselves (Parker, et al. 2007; Wilkinson, et al. 2007; OPASA, 2003).

Legislative development of ACDs in Australia resulted in a variety of Acts of Parliament and legal instruments being drafted in the 1980s (Kerridge, et al. 2009b). South Australia was the first to draft specific legislation in this area through the passage of the *Natural Death Act of 1983* (the Act) which provided statutory authority for ACD use to “*provide for, and give legal effect to, directions against artificial prolongation of the dying process*” (SAG, 1983, p.2). Written at the time in response to the Quinlan case in the USA, the Act did not anticipate the extent of future medical treatment to be applied to people with chronic illness, cognitive impairment or long dying trajectories. To prevent people being subjected to burdensome treatment under these scenarios, a Parliamentary select committee on death and dying was established in 1995 to improve the legislation such that it accommodated decision-making for future medical technologies and longer dying trajectories (SAG, 1995). The result of this committee’s findings was the replacement of the *Natural Death Act of 1983* with the *Consent to Medical Treatment and Palliative Care Act 1995* enabling people to write specific instructions for their care in an Anticipatory

Direction and also appoint a Medical Power of Attorney (MPA) to act as their SDM for any decisions to be made (SAG, 1995).

Following South Australia's lead, by the mid-2000s all states and territories in Australia had legislation incorporating some instrument of ACD or advance care planning (ACP) as defined by the political and ideological frameworks of the jurisdictions involved. These instruments included within most states Enduring Guardianship (NT does not have EPG; WA introduced EPG in 2010) or other means of appointment of SDMs (Kerridge, et al. 2009b). Throughout these jurisdictions however no two legislative Acts or instruments were written quite the same which meant that ACDs and SDMs in one jurisdiction might not be recognised or regarded as valid in other jurisdictions because the Commonwealth Law permits each state/territory to make their own health laws (TCTEPC, 2011; Kerridge, et al. 2009b). The reasons for each state developing different versions of ACDs under differing Acts lies outside the scope of this research however an example of how decision-making arrangements differ is illustrated by the following state comparisons.

Guardians in Victoria are required to make decisions for others based on the best interests of the person while medical agents appointed in South Australia under a MPA must make decisions based on substituted judgement, or what the person would have chosen based on previously written or verbal instructions (Office of the Public Advocate Victoria (OPAV), 2004; OPASA, 2003). The concept of substituted judgement has been recently extended to encompass *contemporaneous substituted decision-making* which enables decisions to be made relevant to the prevailing circumstances but is consistent with what the person would have decided in those circumstances. Contemporaneous substitute decision-making is being considered in South Australia as the preferred approach for guardianship decision-making as described nationally in the *National Framework for Advance Care Directive Consultation* (TCTEPC, 2011). The reason for consideration of this extended version of substitute decision-making is that it permits SDMs to make decisions different to previously recorded ACD instructions based upon subsequent discussions held with the person being represented since the completion of the ACD (TCTEPC, 2011).

The literature identified that the different instruments, different ideological frameworks and varying recognition of different types of ACDs in Australia was not helpful in the development, promotion, or implementation of ACDs (TCTEPC, 2011; Kerridge, et al. 2009b; Brown, et al. 2009). The complexity of the legislation governing these instruments has been identified in the literature as a major reason for the slow uptake and completion by the public of these instruments (Cartwright, 2011; TCTEPC, 2011; SAG, 2008b; 2007b; Wilkinson, et al. 2007; NSWG, 2004; Tan & McMillan, 2004; Fazel, 2000).

As an example of the complex legislation of these instruments, South Australia has three separate ACDs recognised in law as applicable to healthcare and welfare decision-making and two ADs which do not have healthcare decision-making powers (OPASA, 2003). The three ACDs for healthcare and welfare decision-making are the Enduring Power of Guardianship (EPG), which covers health and welfare decisions; the Medical Power of Attorney (MPA), which is limited to medical treatment decisions only; and the Anticipatory Direction (Ant Dir) which is limited to end of life (EOL) medical decision-making. The remaining two instruments, the Enduring Power of Attorney (EPA) and Wills, do not permit substitute decisions about health care (SAG, 2007b; OPASA, 2003). Furthermore, the South Australian EPA only applies to financial and legal decision-making whereas EPAs in other jurisdictions may include a specific section on advance healthcare decision-making. Wills, on the other hand, apply only after a person has died so are not relevant for substitute decision-making while the person is still alive (OPASA, 2003).

In South Australia, the EPG and MPA enable SDMs to be nominated in advance for the purpose of acting for a person in the manner the person nominated for a future time when the person was incapacitated and unable to participate in decision-making (OPASA, 2003). The Anticipatory Direction, in contrast, does not nominate a SDM but includes instructions for types of healthcare and welfare management preferred by the person for a future time when they are in the terminal phase of a terminal illness and cannot voice those decisions themselves (OPASA, 2003).

The South Australian Review Committee on Advance Directive Use (2008-2009) determined that Wills and EPAs were frequently completed

together as part of an estate planning process resulting in the EPA often being the first directive that people identified when asked if they had an ACD (SAG, 2008b; Brown, 2006; Brown & Jarrad, 2005b). This committee found that the EPA was completed through the auspices of a lawyer, solicitor or financial advisor as a result of retirement, changing relationships or the need for institutionalised care (SAG, 2008b).

The common recognition and elocution of the EPA with a Will has led the EPA in South Australia to be mistakenly identified by the public as an ACD with concomitant medical and healthcare treatment decision-making abilities (Brown, et al. 2009; SAG; 2008b). This has led to healthcare and lifestyle decisions incorporated in the wrong instrument, for example an EPA rather than the more appropriate EPG (Brown, et al. 2009; SAG, 2008b; Brown & Jarrad, 2005b). Research by Bravo, et al. (2008) and Jezewski, et al. (2007) found that just because an AD or ACD had been completed it did not necessarily mean that the person completing it actually understood what it did or when it needed to be enacted.

The misunderstanding by the public of the appropriate application, completion and implementation of ACDs may create consequences of purported improperly enacted medical and healthcare decision-making at the behest of illegitimate SDMs (TCTEPC, 2011; SAG, 2008b; NSWG, 2005). This, in turn, generates confusion for healthcare professionals (HCPs) trying to act within the patient's declared preferences (Epstein, et al. 2009; Kirchoff, et al. 2004).

The ability for SDMs to be appointed through means other than an appropriate ACD further complicates the issue. For example, the law permits the assignment of a relative by default, the appointment of a guardian by a court or tribunal and in some states, in an emergency, the appointment by a court of a healthcare professional as SDM (OPASA, 2003; SAG, 1995)

Under these circumstances, the assignment of an SDM is to prevent battery of an individual undergoing emergency or other health, medical or lifestyle management where substitute decision-making is required (McGee, 2011; Kerridge, et al. 2009b; OPASA, 2003). If a nominated SDM through one of these means is not available at the time that decisions are to be made, then decision-making reverts to either the next of kin or other appointed person in

an order of authority which may be defined differently between state and territory jurisdictions (TCTEPC, 2011; Kerridge, et al. 2009b; OPASA, 2003; SAG, 1995).

Not having preferred SDMs properly nominated through ACDs could result in emergency medicine specialists and senior ambulance personnel providing unwanted and unwarranted treatment because they feared legal or professional ramifications in not providing care (Brown, et al. 2009; SAG, 2008b). Having ACDs could prevent this imposed decision-making; yet research internationally, nationally and locally indicated that typically less than 15-20% of the eligible adult population had written ACDs to prevent unwanted treatment at times of crisis with widespread educational efforts to promote use of ACDs in the USA and elsewhere failing to increase completion rates (Castillo, et al. 2011; Wilkinson, et al. 2007; Collins, et al. 2006; Brown & Jarrad, 2005b; Fagerlin et al. 2004).

Recent research by Castillo, et al. (2011) suggests that reasons behind the poor uptake of ACDs, notwithstanding the legal confusions inherent in these instruments, have also included the readability of ACDs, the level of literacy of the public engaging with these instruments as well as the issue of legal recognition of nominated SDMs. Comprehension and literacy requirements for proper enactment of ACDs have been complicated by the issues of competence and capacity or the person's ability to understand the consequences and outcomes of their decision-making (Applebaum, 2006; Glanfield, 2006; Black & Osman, 2005; Nolan, et al. 2005). Competence and capacity for ACD decision-making have been the basis of much of the legal and ethical research conducted in this area (Applebaum, 2006; Glanfield, 2006; Tan & McMillan, 2004; Stroop & Applebaum, 2003; Darzins, et al. 2000).

An example of the effect that poor comprehension of the functionality of these instruments can have on ACD decision-making was demonstrated by research from the South Australian Government Review Committee on Advance Directive Use (2008-2009). Their research found that the public's perception of end-of-life care was broader than that defined in the MPA (medical interventions only) or the Anticipatory Direction (terminal phase of a terminal illness only) and included instructions on where the care was to be taken included in the EPG, MPA or Anticipatory Direction even though these



instruments do not have provision for this type of decision-making (SAG, 2008a;2008b). The Committee's conclusion was that future promotion of ACDs would need to deal with issues beyond medical treatment at EOL and include, but not be limited to, broader health and living arrangements such that the ACDs fit a person's needs rather than the person fitting the content of the current forms (Gibson, 2010; SAG, 2008a; 2008b).

The paradox of having instruments supported by legislation to protect and promote personal autonomy yet be incorrectly written, rejected, implemented or not meeting the needs of the individual has been the foundation of a substantial amount of research over the past two decades (Detering, et al. 2010; Clements, 2009; Bravo, et al. 2008; Jezewski, et al. 2007; Wilkinson, et al. 2007; Collins, et al. 2006; Fagerlin, et al. 2004; Lynn & Teno, 1993). This research resulted in debate for and against the continued use of these instruments to protect personal autonomy in healthcare decision-making. For example, Fagerlin, et al.(2004) and Lynn and Teno (1993) argued that instructional ACDs, such as those in the USA, failed to promote personal autonomy for a number of reasons including; cultural inhibitions, hesitation to face one's own mortality, and not understanding enough about disease or illness to nominate preferred medical treatments. Therefore, they argued, persistence in advocating the use of ACDs should cease (Fagerlin, et al. 2004; Lynn & Teno, 1993). Nevertheless, there has continued to be widespread support politically and philosophically for people to be able to appoint and instruct SDMs through the use of ACDs to preserve at least some element of self determination in healthcare and welfare management (Detering, et al. 2010; Access Economics, 2009; Clements, 2009; Tucker, 2009; Lynch, et al. 2008).

The argument for persisting with ACD use in Australia was supported by recent research internationally and nationally showing that ACD use may be on the rise (Ruff, et al. 2011; Detering, et al. 2010; Bravo, et al. 2008; Austin Health, 2006). In Australia, this rise has been evidenced by an increase in both the number and types of ACDs presented at Australian hospitals, hospices and residential aged care facilities (RACFs) (Detering, et al. 2010; Austin Health, 2006). The increase in use of ACDs has largely been through the efforts of programs like Respecting Patient Choices®-RPC (2008; Austin

Health, 2006). These programs encourage HCPs to assist those with terminal illness or entering RACFs to complete ACDs and ACP (RPC, 2008; Altmore & Naksook, 2007; Austin Health, 2006).

According to the research evidence, those ACDs presented most often in South Australia comprise EPGs (approx 80-90%) followed by MPAs (approx. 15%) and lastly Anticipatory Directions (approx 10%). These findings supported other research that suggested people prefer to appoint SDMs more than completing particular instructional instruments (Detering, et al. 2010; Altmore & Naksook, 2007; Austin Health, 2006). The preference for SDMs indicated that there were other factors influencing this method of preserving autonomy in medical decision-making. The literature revealed that these other factors included ethical values, psychological support or societal influences such as culture (Barbour, et al. 2009; Matzo, et al. 2008; Lynn, 2005; Chan, 2004; Bialk, 2004; Bondoc, 2003; Lynn & Teno, 1993). Ethical factors influencing ACD legislation in Australia were evidenced by the differences between South Australia and Victoria in the manner in which SDMs could make decisions, (e.g. substituted decision-making vs best interests of the patient). Factors underpinning the development of different ethical perspectives of ACD use are explored in the section that follows.

### ***Ethical Perspectives Influencing the Support and Promotion of ACDs***

Ethical perspectives have been a prominent part of the historical and legal development of ACDs. Ethics or values help define both the behaviour and practice of phenomena (Kerridge, et al. 2009a, b; Law, 2007; Kahana, et al. 2004; Harold, 2002). To understand the ethical values that influence ACD decision-making, many researchers have explored the beliefs and values of the various parties involved in application of these instruments (Anderson, 2009; Beauchamp & Childress, 2009; Brown, 2009; Edwards, 2009; Kaldjian, et al. 2009; Bialk, 2004; Kahana, et al. 2004; Banja, et al. 1993). Results of these studies have indicated that two main competing value systems underlie the different ethical perspectives on ACDs (Bialk, 2004). Beauchamp and Childress (2009) described these value systems as ethical principles that underlie the care and delivery of healthcare practice. The four ethical principles they defined were: respect for personal autonomy; beneficence (to

*do good*); non-maleficence (*to do no harm*), and social justice (Beauchamp & Childress, 2009; Kerridge, et al. 2009a). The two value systems in conflict in ACD decision-making have been identified as respect for personal autonomy vs non maleficence (Anderson, 2009; NCB, 2007).

The literature suggested that the adoption of one or more of these ethical principles in healthcare decision-making was influenced by societal factors such as culture (Lopez, et al. 2010; Fagerlin, et al. 2004; Turner, 1996; Lynn & Teno, 1993). Culture is developed through beliefs and customs that define the way occupants of that culture live, including customs associated with good or ill health, life and death (Kerridge, et al. 2009a; Barkway, 2009; Germov, 2009; Turner, 1996).

The philosopher David Hume (2005, p.27) stated that “custom then, is the great guide of human life”. During the 1960s however, the Boomer generation broke all the rules of traditional custom and in doing so changed the ethical basis for how people in democratic societies should act out their lives. For example, with the advent of the birth control pill women embracing the feminist revolution were no longer conscripted to a future of marriage and home-making (Kaplan, 2009; CARES, 1997). As a result of this emancipation, women migrated to universities and the workforce in large numbers. This entry of women into a previously male-dominated culture generated further revolutions in communication, transportation, consumerism, environmentalism and civil rights that changed many previous social conventions and ethical norms (Kaplan, 2009; CARES, 1997; Castles, 1991).

This break with previous societal and ethical norms emphasised a new cultural value of the right to personal autonomy in making lifestyle decisions rather than authoritarian prescriptiveness associated with past generations. The change in ethical values was evidenced in the healthcare sector through development of ACDs which promoted personal autonomy over that of the paternalistic standard of medical practice in the past (Germov, 2009; Kerridge, et al. 2009b). Respect for personal autonomy complemented the liberal democratic ideology of individualism and individual rights central to the political positioning of many democratically-based common law countries (Beauchamp & Childress, 2009; Kerridge, et al. 2009a, b). In contrast, paternalism in medicine engendered a patient/doctor relationship in which the doctor was

seen to be the decision-maker rather than the individual (Germov, 2009). This conflict in ethical values is seen most clearly when an individual refuses life-saving treatments against the advice of medical practitioners whose ethical values encompass preserving life at all costs. The literature revealed that medical practitioners confronted by this situation viewed ACDs or ACP as having an adverse influence on the doctor/patient relationship (Edmonds, et al. 2009; Seale, 2009).

To avoid ethical conflict between HCPs and their patients, the literature identified that implementation of both instructional and ACD instruments required a trusting relationship between patient, medical practitioner, SDMs and HCPs. This trusting relationship needed to be premised on respect for the values of the patient (Durbin, 2011; Barbour, et al. 2009; Tesfa & Meyer, 2008; Chan, 2004). If these values were not known or shared, then ethical conflict could arise between any or all of the parties concerned, jeopardising completion and enactment of ACDs. For example, the paternalistic practice of medicine has been based on the ethical principles of beneficence/non-maleficence (*do good/do no harm*) (AMA, 2006a, 2006b; 2007; Hancock et al. 2007; Seale, 2006). Reasons for adoption of this ethical stance in preference to personal autonomy date back to antiquity but are based on the need for a trusting relationship between medical practitioner and patient to develop (Kerridge, et al. 2009a; Law, 2007). Once such a relationship has been established, the patient develops confidence in the medical practitioner not to engage in practices that could harm the patient (Kerridge, et al. 2009a; Beauchamp & Childress, 2009; Stanley, 1989). With current medical technology however the trade off between QOL with invasive or complex medical treatment has placed this trusting relationship on a less secure base (Sweet, 2010).

Trust by the patient in the medical practitioner may also anticipate that the standard of practice of medicine delivered is based on the best available evidence and will be used in the patient's *best interests* (Coggon, 2008; AMA, 2006a,b). Best interests though may undermine respect for personal autonomy when the interpretation of best interests is made by others with presumed knowledge of what would help the patient most or who have a different value system to the patient (Kerridge, et al. 2009a; 2009b; Coggon, 2008).

The medical practitioner who defines their duty of care to patients through a best interest approach may be influenced by the ethical principles of beneficence/non-maleficence (Coggon, 2008; New South Wales Department of Health (NSWDH), 2010). If this is the case, the medical practitioner may override an ACD that refused medical interventions to prevent harm to the patient as the medical practitioner may not feel that the ACD is in the patient's best interests (Anderson, 2009; AMA, 2007; Coggon, 2008).

The literature described that medical practitioners sometimes justify overriding refusals of treatment because they believe they have more knowledge about the patient's condition and outcomes than the patient or SDM (Cartwright, 2011; Schwarze, et al. 2010; Anderson, 2009; Camhi, et al. 2009; Reuben, 2009; Berger, 2008; Deep, et al. 2008; Hancock, et al. 2007; Seale, 2006; Nolan, et al. 2005; Back, et al. 2002). Patients and SDMs who challenge this medical practice with autonomy as expressed through an ACD are seen as having broken the trust relationship expected by the medical practitioner hindering the medical practitioner's acceptance and implementation of the ACD (Schwarze, et al. 2010; Coggon, 2008; Deep, 2008).

To alleviate some of the tensions arising from a conflict of ethical perspectives, many medical practitioners and HCPs have admitted that clarity of a person's values and decision-making through ACDs would be; advantageous, reduce clinical confusion and error in treatment, and relieve the burden of decision-making from SDMs (Austin Health, 2006; Brown, 2006; Seale, 2006; , Brown et al. 2005a; Brown & Jarrad, 2005b; Nolan, et al. 2005). Recent studies have indicated that if this clarity is not evident tensions in care management caused by ethical conflict can create moral distress for medical practitioners, other HCPs, patients, family members and SDMs (Wendler & Rid, 2011; Salmond, 2011; Repenshek, 2009; Birch & Draper, 2008, et al. 2008; Seale, 2006; Fins, et al. 2005; Costello, 2002). This ethical conflict then creates psychological or moral distress for HCPs and SDMs as they are expected to make decisions for others, sometimes many times over many years for those with chronic illness, (e.g. dementia) (Melhado & Fowler Byers, 2011; Deep, et al. 2008; Brown, 2006; Jennings, 2006). The psychological impact on these parties and the moral distress caused by such

decision-making has become the focus of more recent literature in the area of ACD administration and is discussed in the following section.

### ***Psychological Effects of Acting as an SDM in ACD Implementation***

In consideration of the psychological impact of acting as an SDM, Bravo et al. (2008) and Jezewski et al. (2007) argued that the role of SDM was being impacted upon and hindered through misunderstanding by SDMs and the people they represented of the conditions of application and implementation of ACDs. The lack of clarity and knowledge of ACD application and implementation were seen to be dominant factors for psychological distress for SDMs as they strive to do what they feel the person wanted but may neither have the authority or the appropriate knowledge for doing so (Bravo, et al. 2008; Jezewski, et al. 2007). To alleviate psychological or moral distress at these times and prevent unwanted or unwarranted treatment being provided, the literature emphasised the importance of including SDMs as part of the healthcare decision-making process (Wendler & Rid, 2011; Jox et al. 2008). To help address moral distress so that it would not lead to psychological ill health, the literature suggested that collaborative communication was required by all parties engaged in decision-making for someone else.

Collaboration in communication and decision-making requires clear and consistent understanding of ACD instructions through multiple episodes of communication between the patient, their family and the healthcare team (Wendler & Rid, 2011; Clements, 2009; Jox, et al. 2008; Tesfa & Meyer, 2008; Austin Health, 2006; Ford, 2006). Appropriate application of an ACD involves all parties developing a holistic understanding of the individual through repeated episodes of communication (Wendler & Rid, 2011; Barbour, et al. 2009; Martin & Roberto, 2006). Although all parties may feel they have communicated appropriately, the literature revealed that this communication did not always occur in a timely and sufficient manner, especially in the acute care environment (Wendler & Rid, 2011; Edmonds, et al. 2009; Deep, et al. 2008; Decker, et al. 2007; Black, 2006; Ford, 2006). When communication was delayed or insufficient, then SDM decision-making may not reflect what was anticipated in the ACD, negating the benefit of completing an ACD and

creating conflict between all of the parties as well as moral and psychological distress.

Making appropriate decisions for someone else through a collaborative healthcare approach could be hindered if any of the parties involved in the care of the patient had a bias against the right of SDMs to make decisions on behalf of another person (Melhado & Fowler Byers, 2011; Jox, et al. 2008; Shalowitz, et al. 2007; Nolan, et al. 2005). The legal and ethical responsibilities of SDMs to act for and on behalf of someone with cognitive impairment or a long dying trajectory generated substantial amounts of opinion and research in the literature on the extent and intent of medical and healthcare decision-making that SDMs should be allowed (Wendler & Rid, 2011; Melhado & Fowler Byers, 2011; Access Economics, 2009; Anderson, 2009; Jox, et al. 2008; AG, 2007; Shalowitz, et al. 2007; AHMC, 2006; Nolan, et al. 2005). Arguments in the literature identified that these differences of opinion were underpinned by differences in ethical perspectives and exacerbated the psychological impact of responsibility for decision-making on those making and affected by the decisions being made, including SDMs, patients, families and HCPs (Durbin, 2011; Salmond, 2011; Wendler & Rid, 2011; Khodyakov & Carr, 2009; Cartwright & Parker, 2004). The moral distress caused by ethical conflict and bias against SDM decision-making was felt not only by SDMs, but also by HCPs not able to provide the care a person may have wanted (Melhado & Fowler Byers, 2011; Salmond, 2011; Repenshek, 2009; Fins, et al. 2005). Moral distress engenders mental and emotional fatigue by SDMs required to engage in decision-making multiple times over a long period of time (Wendler & Rid, 2011; Salmond, 2011; Khodaykov, et al. 2009; Jennings, 2006).

When healthcare professionals debate the role of the SDM, they also risk undermining the confidence of SDMs to make decisions as well as HCP confidence to act upon the decisions made by SDMs (Wendler & Rid, 2011; Barbour, et al. 2009; Kaldjian, et al. 2009). To prevent this from happening, the literature suggested assisting SDMs to fulfill their role through HCPs committing to engage the SDMs in ongoing consultation and communication in a collaborative approach (Anderson, 2009; Hancock, et al. 2007; Brown, 2002; Layson, et al. 1994; Banja, 1993). Doing so would ease the moral distress of

all of the parties engaged in the decision-making as all parties would be aware of and have discussed the decisions to be made (Propp, et al. 2010; Deep, et al. 2008; Black, 2006).

The literature described the most often cited reason for not being able to generate collaborative decision-making in a timely manner was that patients and/or their family were not prepared to discuss this type of decision-making without competent professional assistance (Ford, 2006; Seale, 2006; Cartwright & Parker, 2004; Brown, 2002; Layson, et al. 1994). Professional assistance was most often sought from the patient's general or medical practitioner. General practitioners however were shown to be frequently reluctant to discuss ACDs with their patients if they felt that a patient was under distress, heavy pain management or in the terminal throes of illness (Berger, 2008; Deep, et al. 2008; Jennings, 2006; Brown, 2002; Carresse, 2002; Layson, et al. 1994). A study by Carrese et al. (2002) found medical practitioners thought it disadvantageous to conduct ACD discussions with elderly people in acute illness when prognosis was difficult to determine because their capacity to survive the crisis could be higher than anticipated. Sessanna et al. (2008) also found that medical practitioners lacked knowledge about how to initiate ACD discussion and privately believed that ACD discussions were time intensive and costly.

To refute the medical practitioner perspective, the literature provided substantial evidence that better pain management and EOL care was delivered when ACP instruments, including ACDs, were completed as part of a collaborative discussion between medical practitioner, patient, SDM and family members (Rigby, et al. 2010; Clements, 2009; Austin Health, 2006). Patients with long-term conditions such as dementia especially benefitted from these discussions, particularly at the early stage of diagnosis. These early discussions ensured that the person with dementia maintained some aspect of autonomous decision-making that would be respected at a later time of incapacity (Cartwright, 2011; Access Economics, 2009).

Capacity for decision-making by the person with dementia also generated a substantial amount of literature on ACD use but in-depth exposition of these arguments is outside the scope of this research. Mezey et al. (2000) however found that physicians and nurses who held biases and



beliefs regarding healthcare treatment preferences of people with dementia presumed the person with dementia could not or had not fully considered, discussed or decided upon their treatment preferences with others when often this was not the case. Ignoring the advance, expressed wishes of people with chronic illness, such as those with dementia, results in decisions being made that prolong or prematurely end life or create inferior quality of life for that person (Cartwright, 2011; Access Economics, 2009; Brown, 2006). This situation contravenes the person's right to self determination in future healthcare decision-making (Cartwright, 2011; Access Economics, 2009). Biases against certain groups being able to act autonomously, for example the person with dementia, may reflect a shift in societal and ethical attitudes on healthcare delivery and resource use for these groups which can undermine ACDs. Examination of possible societal factors influencing the provision of healthcare delivery or resource use in association with ACD decision-making is discussed in the section that follows.

### ***Societal Factors Impacting on ACD Decision-making***

The literature described societal factors which could deprive some socioeconomic groups from accessing appropriate healthcare or decision-making because of their background (van Beek, et al. 2010; Collins, et al. 2006; Lynn & Teno, 1993). This was because groups in lower socioeconomic circumstances may have limited resources to obtain high levels of healthcare or not be empowered to do so (Germov, 2009). The literature described that in some cases, actually having ACP or ACDs could be disadvantageous for these people when healthcare funding was reduced and those who completed an ACD could end up receiving care that did not prolong life because they were poor, homeless, had drug and alcohol or other issues (Vo, et al. 2011; Lopez, et al. 2010; van Beek, et al. 2010; Barone, et al. 2009; Fetherstonhaugh, 2009; Matzo et al. 2008; Brown, et al. 2005a; Brown & Jarrad, 2005b; Chan, 2004; Inman, 2002). Barone et al. (2009) found that individuals over the age of 65 from lower socioeconomic levels were disadvantaged in both mortality rates and treatment according to clinical guidelines for hip fractures more than affluent individuals, despite both groups being in a universal healthcare system. Vo et al. (2011) found that residents of

RACFs cared for by older workers had fewer Medical Orders for Life-Sustaining Treatment (MOLST) created and when these orders were created, less care was subsequently provided to them.

This type of decision-making by HCPs about who receives what types of treatment has not been without precedent and has been influenced by considerations of both medical futility and healthcare resource distribution (Schneiderman, 2011; Schwarze, et al. 2010). An example of these considerations influencing medical treatment allocation was provided by Fetherstonhaugh (2009). In her research, she described that early in the days of dialysis treatment in Australia, implicit rationing of dialysis by medical practitioners was based on the age, co-morbidities and location of patients as well as whether patients would be compliant with their treatment rather than the individual's need/want for the treatment (Fetherstonhaugh, 2009). This reflected the parameters associated with distribution of dialysis resources and the attending quality of life. Now however, the parameters of medical futility have shifted such that 46% of people getting dialysis are over the age of 65, reflective of longevity having changed the parameters for defining QOL with age alone no longer being an inhibiting factor for dialysis treatment in some countries (Fetherstonhaugh, 2009).

Though age was no longer considered a limiting factor for medical treatments which could extend life, having co-morbidities was seen to be a limiting factor (Gibson, 2011; Fetherstonhaugh, 2009). Gibson (2011) summarised several studies showing that the use of healthcare services and resources soared in the last 6 months of life for people with heart failure due to this group typically having four or more co-morbidities. For people to receive the appropriate level of healthcare to match their conditions without accessing unnecessary and expensive healthcare resources, Gibson (2011) recommended that medical practitioners hold more conversations with their patients to encourage and support them to define what quality of life meant to them and to ensure they had a better understanding of their illness trajectory. These types of conversations would then engender respect for personal autonomy as well as equitable healthcare resource distribution.

The future beneficiaries of the conversations recommended by Gibson (2011) will be the Boomers. This demographic group is witnessing the use of

healthcare resources for more and more people living longer lives with chronic illness engendering a globalised concept of what QOL means including length of time to live and what can be done with that life as a member of society (O'Loughlin, et al. 2010; Humpel, et al. 2009; Matwijiw, 2009b; Higgs, et al. 2003; WHO, 1997). As the conversations with Boomers about healthcare and welfare decision-making increase, the impact of historical, legal, ethical, psychological and societal factors informing their experience of substitute decision-making and ACDs will be revealed. The following section discusses how the contextual factors of ACD decision-making discussed in previous sections may influence Boomer ACD decision-making.

### ***The Context of ACD Decision-making for Boomers***

It was speculated in the literature that the Boomers and the generations following them would have an expectation of living longer lives largely because advancements in medical technology have enabled previous generations to do so (Rubin, 2007; Gillick, 2006). Medical technology enabled these previous generations to live much longer than anticipated because of medical advancements that eliminated death from childhood illnesses, maternal mortality, accidents and pneumonia which have also benefitted the Boomers (O'Loughlin, et al. 2010; Rubin, 2007; Gillick, 2006; ABS, 2003; CARES, 1997). Living through a time when death has been circumvented has meant that Boomers have witnessed more people living beyond 85, including the fastest growing demographic in Australia of those who are 100 and older (ABS, 2006b; 2006c). Boomers have also witnessed however that increased longevity has not always been accompanied by good health. This has meant that for Boomers acting as SDMs and even Boomers themselves, they have had to engage in more healthcare and welfare decision-making due to increasing chronic illness in a way unlike that of previous generations (Salmond, 2011; Wendler & Rid, 2011; Matwijiw, 2009b). When engaging in this decision-making, those Boomers guided by the ethical imperative of autonomous decision-making will be challenged in upholding this perspective for others when future medical and healthcare treatments are rationed due to a dwindling ability for governments to be able to provide similar levels of care to

that currently being experienced by earlier generations (AG, 2010a; AG2020, 2008; ABS, 2006b,1997).

Organisations such as the World Health Organisation (2009) as well as governments around the world, including Australia, have understood the implications of these contextual factors for the Boomer generation. These government bodies have begun developing policy for ACP, ACDs and healthcare resource allocation to meet the expectations of healthcare and welfare in the future (TCTEPC, 2010; WHO, 2009; NCB, 2007; Mathers & Leonardi, 2000).

Concern that healthcare resources could be compromised for the Boomer demographic was demonstrated by the South Australian Minister for Health who pleaded for better clinical decision-making for the terminally ill and frail aged before a “tsunami of demand” for healthcare depleted the entire State budget (Shepherd, 2009, p.1).

Additionally, the Palliative Care Services Plan released by the South Australian Department of Health stated: “future workforce supply (of healthcare workers) indicates a complete inability to maintain workforce groups at current numbers into the future” (SAG, 2009b, p. 3). Within these parameters of resource demand and workforce depletion, what Boomers in South Australia can expect for healthcare services toward the end of their lives may be markedly different to what their parents and others have and are experiencing (Humpel & O’Loughlin, 2010; Beer, et al. 2009; SAG, 2009a; ABS, 2003).

Australian state governments, such as those in South Australia, Victoria and New South Wales have understood that to provide appropriate healthcare and welfare that respects personal autonomy, people must discuss future choices with others and that the option of just relying on the government to provide what is necessary is no longer tenable (PC, 2011; RPC, 2008; SAG, 2008b, 2008c; NSWG, 2004). The literature suggested that the most acceptable means in which to generate this discussion was through medical practitioners, HCPs and families discussing ACP and ACDs as part of a regular healthcare planning process. Doing so would enable targeted healthcare and welfare decision-making that respected the autonomy of the patient and prevented wanton or unnecessary use of diminishing healthcare

resources, especially for chronic disease states where QOL becomes the issue.

Embracing the concept of ACDs at a time of chronic illness is particularly appropriate for the Boomer generation as they are predicted to age with multiple co-morbidities, such as diabetes and obesity, beginning at younger ages than evidenced in the past (AIHW, 2010b; AG2020, 2008; ABS, 2006a). These co-morbidities and the chronic illness states associated with them will linger over longer periods of time because medical advancements in these areas are controlling the symptoms of these diseases enabling longevity and QOL where once there would have been death (DHA, 2008). Controlling the symptoms of these diseases does not, however, negate the need for ACDs. Indeed, repeated admissions to hospital and outpatient clinics for symptom management demands that ACDs be completed so appropriate care is provided based on the individual's choices, rather than on what medicine can do to extend life (Camhi, et al. 2009; Reuben, 2009).

To counteract the presumed future demand for increased healthcare and welfare services by the longer lived chronically ill, Boomers have been targeted and encouraged to adopt *healthy ageing* lifestyles. Healthy ageing lifestyles encourage people to give up the risky habits relied upon to cope with the stresses of everyday life, such as smoking, overeating, drinking alcohol and taking recreational drugs (DHA, 2008; Ebersole, et al. 2008). The concept of healthy ageing has been promoted as an antidote to the Boomer propensity for unhealthy ageing and associated co-morbidities, but puzzlingly, this opposition to unhealthy ageing also promotes opposition to death itself (Janvier, 2010; Russell, 2010; Borbasi, et al. 2005). Encouraged delay of the dying process means that Boomers face the prospect of having to decide not only at what stage life should cease for those they are acting for as SDMs, but also at what stage life should cease for them (Dore, 2009; Varki, 2009; Dobratz, 2002). This latter point has been explored in South Australia and Australia over many years through community and parliamentary debate on legislating voluntary euthanasia without resolution and preventing the ability of complete autonomy in end of life decision-making (Richardson, 2010; & Wood, 2009, et al. 2009; Australian Nursing Federation (ANF), 2007; Royal College of Nursing, Australia (RCNA), 2006).

Therefore, the context in which Boomers engage with ACDs may be one of necessity, demand, or choice which, unlike previous generations, will be influenced by knowledge, awareness and understanding of the need for healthcare and welfare decision-making influenced by many of the factors described in this chapter.

### ***Summary***

This contextual literature review has highlighted the trends and patterns of historical, legal, ethical, psychological and societal factors that have impacted the development and use of ACDs in democratic societies. The historical context of ACDs was described through case studies in the USA that described medical advancements delaying death and impacting on QOL. Within this context, the Boomers were maturing amidst social revolutions that changed previous cultural values from authoritarian paternalism to respect for personal autonomy. For democratic societies, respect for personal autonomy became embedded in all aspects of life and death at this time, including in healthcare and welfare decision-making. The result of this change in cultural values in the medical arena was the invention of ADs in the USA to preserve personal autonomy in future healthcare and welfare decision-making. Legislative support for ADs in the USA was maintained by the Patient Self Determination Act (1990). This act provided the basis for AD development in other countries like Australia. Legislative support for ADs in Australia resulted in a variety of instruments across jurisdictions based on different ideological frameworks. This led to poor uptake and implementation of ADs across Australia because validation and acceptance of these instruments across state and territory borders was inconsistent and a significant impediment to the use of these instruments.

Legislative inconsistency was seen to be caused by different ethical frameworks underpinning the manner in which SDMs should engage in decision-making for others. These different ethical value systems also caused conflict between medical practitioners and patients who had contrasting ethical perspectives. Medical practitioners were seen to be guided by the ethical principles of beneficence/non maleficence to act in the patient's best interests. If medical practitioners were presented with ACDs by patients who held an

ethical imperative of respect for personal autonomy, trust in the patient/medical practitioner relationship could be undermined as the balance of medical decision-making power shifted from the medical practitioner to the patient. These kinds of ethical conflicts were demonstrated to cause moral and psychological distress for the parties involved further undermining the willingness of people to engage with ACDs as SDMs for others or to implement ACDs appropriately.

Psychological and moral distress was accentuated for SDMs and HCPs when ACDs were not made clear or discussed in advance. To avoid such psychological distress, it was established that patients, SDMs and HCPs needed to engage in collaborative communication with the medical practitioner about medical treatment decisions. Medical practitioners hesitated to have these discussions due to practical limitations of time and patient acuity as well as not knowing how to conduct the conversation. Hesitation in having ACD conversations with patients was further exacerbated if medical practitioners and HCPs had preconceived biases or ethical conflict about autonomous decision-making for particular demographic groups, such as people with dementia. These biases were hypothesised to reflect the influence of societal factors such as culture and context of previous healthcare treatment provided to other demographic groups. This was illustrated in the literature through description of the higher morbidity statistics for lower socioeconomic patients and the withholding of life extending treatment to those with multiple co-morbidities.

Lastly, this contextual literature review described why ACDs were particularly important to the Boomer generation and how all of the different contexts described may influence their use of ACDs. Factors relevant to the Boomers included: the Boomer propensity for personal autonomy in decision-making; diminishing healthcare and welfare resource availability, and Boomer workers living longer with chronic illness. As Boomers experience more chronic diseases during their ageing, the literature suggests this will require them to engage with the healthcare system on a more frequent basis necessitating multiple decision-making events. Their experience of decision-making in this context will influence their own future ACD decision-making as well as the decisions they make for others in the role of SDM.

If Boomer decision-making is to reflect autonomy and healthcare provision in a democratic fashion consistent with Australian values, a concerted effort is necessary for understanding this generation's expectations of future healthcare and welfare decision-making. Evidence of what these expectations might be was discussed throughout this contextual literature review and constitutes a preliminary understanding of how the factors presented in this chapter may influence SA Boomer ACD decision-making. The following chapter describes the next step in this understanding; the use of classical grounded theory to understand the subjective experience of this decision-making.



### **Chapter 3 – Methodological Approach for Identifying Factors Influencing SA Boomer ACD Decision-making**

This chapter will describe the methodological approach and method used to answer the research question “What factors influence ACD decision-making by Boomers in South Australia?” The chapter begins with an introduction describing the choice of methodological approach then proceeds in sections to describe why this approach was taken and how it has been applied in this research.

In considering the best approach for identifying factors influencing ACD decision-making by SA Boomers, a methodology was required that could produce a rigorous interpretation of these factors from the subjective experience of a sample of SA Boomers. To explore subjective experiences, a qualitative methodological approach that provided in-depth, personal experience of a phenomenon was used to answer the *how and why* of ACD decision-making by this sample (Holstein, et al. 2005; Morse & Richards, 2002; Denzin & Lincoln, 2000; Stern, 1980). A particular type of qualitative methodology used by many in the sociology and nursing arena to explore the subjective experience of a phenomenon is grounded theory (Morse & Richards, 2002; Denzin & Lincoln, 2000; Stern, 1980).

Classical Grounded Theory (CGT) by Glaser and Strauss (2008/1967) was found to be the most suitable for the purposes of this research. Classical Grounded Theory involves interviewing; observing and reviewing data using constant comparative analysis to uncover core categories of meaning that describe the behaviour and practice of individuals or groups experiencing a particular phenomenon in a particular context (Glaser, et al. 2008/1967; Denzin & Lincoln, 2000; Stern, 1980). This methodological approach provides a process for developing theoretical understanding of factors influencing specific behaviours and practices. Theoretical understanding of one group’s experience of a phenomenon, such as a sample of SA Boomers ACD decision making experience, can then be compared with theories developed for other groups experiencing the same phenomenon to provide a more robust and comprehensive explanation of the behaviour.

A detailed description of how both the methodology and method of CGT were used in this research will be described in this chapter through:

- Analysis of the philosophical foundation underpinning qualitative methodology;
- Description of the qualitative CGT methodology;
- Applicability of the CGT methodological approach in this research
- Describing the CGT theoretical development process and its use in this research, and finally,
- Describing the method in which CGT was used for this research.

### ***Analysis of the Philosophical Foundation Underpinning Qualitative Methodology***

To justify the use of one research design over another, Chamberlain (2000) suggested that researchers who were investigating issues more subjectively should establish their epistemological and ontological perspectives, including theoretical perspectives, before establishing the methodology and method of their research. If the epistemological and subjective perspectives suggested that the research question should be answered in an in-depth manner to generate new and original knowledge, then using a qualitative method that acknowledged the subjectivity of the experience would better suffice over more objective methodological approaches (Chamberlain, 2000).

A sociological theory used to identify the subjective experience influencing particular human behaviours is *symbolic interactionism* (Denzin & Lincoln, 2000). This theory emphasises that “people are social constructs who act on things based on the meaning those things have for them and that these meanings are derived from social interactions and their influences” (Society for the Study of Symbolic Interactionism, 2011). Symbolic interactionism is a theory that identifies both the epistemological and ontological perspectives of behaviour and practice; however, at the

time that this theory was developed, competing theories promoting more objective, scientific knowledge about human behaviour were being championed to validate knowledge and make it more generalisable, or applicable to other groups across multiple settings (Morse & Richards, 2002; Denzin & Lincoln, 2000).

Against the increasing emphasis of objective knowledge, Glaser and Strauss (2008/1967) developed CGT to act as a bridge between the objective and subjective understanding of phenomena. This bridge was accomplished through development of empirical methodology that acknowledged and verified in a rigorous approach the subjective understanding of the behaviour under investigation (Glaser, et al. 2008/1967; Morse & Richards, 2002). By constructing CGT in this manner, Glaser and Strauss extended the concept of symbolic interactionism to include a critical realist perspective which validated the subjective in an objective process (Morse & Richards, 2002; Guba, 1990).

Guba (1990, p. 23) asserted that critical realists become 'modified objectivists' who accept that knowledge is inexact but in exploring the subjectivity of this knowledge, use external parameters that are critically acceptable and open to review to accede to the inexactness of what is learned. Researchers, who operate from a critical realist perspective, continue to think and use objectivity as an ideal way of approaching knowledge generation but also understand that this knowledge remains imprecise (Guba, 1990). Application of the critical realist perspective to subjective understanding of phenomena enables definition of the meaning of actions imposed through societal constructs and combines two different epistemological approaches to knowledge generation that enable both meaning and action to be explored together (Denzin & Lincoln, 2000). Glaser and Strauss (2008/1967) understood that to study a phenomenon from the perspective of the person experiencing it over time and within the social processes occurring, a method was required that could create both objective and subjective understanding of a phenomenon situating it within the context from which it arose (Glaser, et al. 2008/1967). This marriage between the qualitative or subjective understanding of knowledge and the quantitative or objective understanding of knowledge

through methodological application that was robust and descriptive was unique at the time of CGT's development and subsequently extended the range of qualitative approaches available today for subjective understanding of knowledge (Denzin & Lincoln, 2000).

### ***A Description of CGT Methodology***

To explain phenomena from both an individual and societal perspective, CGT seeks to generate theoretical understanding of a phenomenon not only from the 'ground up' but also as it occurs over time (Stern, 2009; Glaser, et al. 2008/1967). Classical grounded theory is able to describe behaviour in this manner through the use of the empirically derived method of *constant comparative analysis*. Constant comparative analysis (CCA) verifies data whilst, at the same time, enabling conceptually abstract theory to unfold as the behaviour is impacted by time and changes in societal constructs (Stern, 2009; Glaser, et al. 2008/1967; Morse & Richards, 2002).

Glaser and Strauss (2008/1967) were able to develop this analysis method because of their experience of qualitative social science research methods using interview techniques with direct or indirect observation to record phenomena. Interviews and observation as used in social science research facilitate data collection from the source of the phenomenon under investigation rather than through experimental or modified means (Morse & Richards, 2002; Denzin & Lincoln, 2000). Data collected through interview and observation is seen as being a product of knowledge in a local context or *natural setting* (Morse & Richards, 2002; Denzin & Lincoln, 2000). Information produced in this manner situates the data from where it arose, (e.g. the person and substantiated the behaviour observed) (Glaser, et al. 2008/1967; Guba, 1990). Stern (1980, p. 21) identified that the "grounded theorist looks for process". Glaser and Strauss (2008/1967) demonstrated this process through coding data in a manner that was both systematic and comparative across and within interviews.

Artinian (1998, pp. 5-6) suggested that using the CCA method with interview and observation provides 'a way to transcend experience' and bring meaning to action and behaviour. Transcending experience is

accomplished when categories or themes arising out of the data are integrated with other categories to provide evolution of phases of knowledge. These phases of knowledge describe the basic social psychological process (BSPP) influencing the behaviour for the people or subject under investigation (Glaser, et al. 2008/1967; Artinian, 1998; Glaser, 1978). Identifying the actual BSPP is preferable to just describing the data as the BSPP provides context, meaning and action connecting the physical, psychological and societal elements of the phenomenon within the specific context of those being investigated.

The BSPP is identified through developing theoretical sensitivity of the researcher to the data as it is analysed using CCA. Theoretical sensitivity provides the opportunity for new theory generation that respects and reveals the perspective of those being researched as well as preventing data collected from being forced to conform, describe or be coerced into following other theoretical positions (Stern, 2009; Glaser, et al. 2008/1967; Morse & Richards, 2002; Glaser, 1978). Glaser and Strauss were particularly sensitive to new data not being forced to follow other theoretical positions because this was seen as corrupting the rigour and context of the new theory (Morse & Richards, 2002; Glaser, 1978).

To test that emerging theory identifies the subjective perspective or experience of those being researched, CGT requires additional participants, purposively sampled to compare against the original population. These purposively sampled participants need to be interviewed or observed in the same manner as previous participants with data arising from subsequent participants to be analysed through CCA. Applying CCA to subsequent participants tests theoretical sensitivity through comparing meaning and action from one participant group to another over time until the core category or BSPP was confirmed (Glaser, et al. 2008/1967).

The explanation of how a behaviour develops over time in a particular context has been an important methodological consideration for this research as the intention has been to provide insight of seven SA Boomer use of ACDs at the same time that government policy is being considered for promotion of ACD use in younger age groups. Classical

grounded theory provides both the methodological perspective and method for researching this decision-making over time. The use of CGT however required consideration of different aspects of the methodology and method and the manner in which both were to be applied as described in the following section.

### ***CGT Methodology as Applied to this Research***

The first methodological consideration Glaser and Strauss (2008/1967, p. 37) suggested for researchers using CGT was that they did not explore the literature in-depth prior to data collection to ensure that theoretical categories emerging from the research were not 'contaminated by concepts more suited to different areas'. This was to prevent 'opportunistic use of theories with dubious fit and working capacity' which they called *exemplifying* (Glaser, et al. 2008/1967, p.37). Glaser and Strauss (2008/1967) suggested that if the researcher was exemplifying with the data this could lead to an emphasis on data fitting prescribed themes rather than themes or categories emerging from the data itself.

Adoption of this pre-theoretical approach for this research resulted in the formation of the contextual literature review in Chapter Two describing the background of ACD and Boomer development rather than particular philosophical or legal positions on ACDs or the Boomers. Constructing the literature review in this manner prevented *exemplifying* of theoretical positions established for and against ACDs or the Boomers and enabled informed sampling of participants that was open and purposive.

#### ***Open and Purposive Sampling***

It was suggested by Glaser and Strauss that the sampling technique in the early stages of CGT should be kept as open as possible so data collection captured as much information about the factors and context influencing the behaviour being studied as could be obtained (Glaser, et al. 2008/1967). Open sampling also needed to be conducted purposively however, to ensure the appropriate participants were being researched for the phenomenon under investigation. Purposive sampling could be accomplished through; using the knowledge gained from background

reading on the issue, personal or professional observations of the issue at hand, and/or conversations with colleagues and others as to which participants would best meet eligibility for the research (Glaser, 2008/1967). For example, because much of the literature applicable to this research had already discussed ACDs for the frail aged, the sampling process for participants in this research excluded anyone over the age of 62 at the time interviews took place. This strategy kept the sampling open yet purposive of the demographic group being investigated, (e.g. SA Boomers).

In contrast to those already known to be engaging with ACDs, this research sought to contribute new and original knowledge of ACD decision-making by recruiting a participant group that had not previously been discretely studied and for whom ACDs had actually been designed for, (e.g. those who are healthy and competent to create ACDs without the added complications of illness or old age). Recruiting members of the Boomer generation fulfilled the intent of this research as well as participant sampling criteria as the Boomers are, in general, still relatively healthy, are able to complete ACDs and should be doing so, yet evidence suggests they are not.

### *Selective or Theoretical Sampling*

Once the stage of purposive sampling was completed, Glaser and Strauss (2008/1967) advised the need to continue to purposively sample additional participants in subsequent stages. These next stages of sampling were to be informed by concepts or factors identified by previous participants as influencing their behaviour. These subsequent stages of participant sampling are called *selective or theoretical sampling*. Theoretical sampling is both a deductive and inductive process of sampling both participants and concepts based on expansion or limitations of concepts arising from data analysis (Glaser, et al. 2008/1967; Morse & Richards, 2002; Stern, 1980; Glaser, 1978).

Theoretical sampling of participants for this research was conducted from one interview to the next as concepts emerged from each interview that identified particular participants to research for the next interview. For

example, the first participant identified themselves as being employed as a healthcare professional (HCP) whilst the second interviewee did not. Subsequent recruitment of participants concentrated on capturing more of both groups to identify similarities and differences in their ACD decision-making. This resulted in two participant groups in this research (HCP, n=5; Layperson, LP, n=2) whose experience of ACDs differed because of their employment in the healthcare system.

When no new factors that might influence participant sampling have been identified, then sampling is considered complete and the *data is saturated* (Glaser, et al. 2008/1967; Morse & Richards, 2002; Stern, 1980). The method used to identify factors leading to data saturation is discussed in the next section.

### *Coding*

As data is collected from participants, it is coded through the process of constant comparative analysis (CCA) (Glaser, et al. 2008/1967). This method of coding involves analysing words, either as expressed by the participant or defined by the researcher that describe the actions or context of the information conveyed (Glaser, et al. 2008/1967). Coding with CCA begins with what Glaser and Strauss (2008/1967) call *open coding* and is then followed by *substantive* or *theoretical coding*. Another form of coding, called *axial coding* is discussed separately.

### *Open Coding*

The first level of coding, *open coding* was described by Glaser and Strauss (2008/1967) as a process by which the data should be examined *line by line* or sentence by sentence until concepts are identified that fit the data. For example, in this research, a participant says “I know about ACDs because of my mother’s death”. In open coding of this sentence, concepts arising included *knowledge, experience, relationships* and *death*. Open coding of this sentence assisted the researcher to focus on both meaning and action from the singular expression to the more complex. This type of *micro* coding expanded to the *macro* when whole phrases of similar meaning were coded against the previous micro-code to indicate broader



meaning of the concept being repeated between participants. Open coding using both the micro and macro technique was conducted line by line for all interviews using the QSR NVivo 8® computer software program to sort and categorise data. An example of the codes developed through this process can be seen in Appendix 2.

When coding or analysis was stopped, memos enabled resumption of the process without any distortion or external corruption of the data. This was as Glaser and Strauss intended as both codes and memos represent stepping-stones to development of categories, core category and eventual theory which remain integral to the data collected, rather than through researcher interpretation (Glaser, et al. 2008/1967).

To keep the coding moving through constant comparative analysis, it is important to keep the group under comparison constant and clear with subsequent comparisons of others against this group to be tracked accordingly (Glaser, et al. 2008/1967). For this research, of the two groups that emerged during participant sampling (HCP and LP) those with HCP experience were chosen as the group to be compared against as HCPs had double exposure to ACDs in both their personal and professional lives.

Glaser and Strauss (2008/1967) suggested that a way to keep track of information arising between groups was to use two different types of open coding. These two different types of code were referred to as *in-vivo* or *substantive* codes. In-vivo codes reflected verbatim what the participant had actually said whilst substantive codes were those which the researcher created to reflect the action or meaning being discussed between and within the groups (McCallin, 2009; Glaser, et al. 2008/1967; Glaser, 1978). Substantive codes were so named because 'they codified the substance of the data' or created meaning from the information provided (Stern, 1980, p. 21). Substantive codes were also called *theoretical codes* as they attempted to define the data 'in theoretical rather than descriptive' terms (Stern, 1980, p. 23).

Creation of both in-vivo and substantive codes through open coding in this research study revealed patterns of a basic social psychological process (BSPP) influencing individuals. Moghaddam (2006) suggests

these patterns can be ascertained from the data whether the individuals are aware of the process or not. For example, in this research, it became evident that some participant knowledge of ACDs was gained through an experience that contributed to awareness or observation of ACD use. In-vivo codes of awareness and experience were created as verbatim from participants, for example 'I was aware' and 'my experience'. Participants often expressed their experience of ACDs using these words. In describing the relevance of how these experiences generated knowledge of ACDs the researcher also created the substantive code of *knowledge*. This substantive code provided a broader meaning encompassing multiple factors that contributed to the knowledge and experience of ACDs. When creation of in-vivo and substantive codes as well as the properties that inform them are complete, the second stage of analysis called substantive or theoretical coding, begins as described in the next section.

#### *Substantive or Theoretical Coding*

Substantive or theoretical coding involves creating a visualisation of the concepts generated in such a way that themes running through the data could be identified (Stern, 1980). Categories informing each other are then integrated to form a core category or theme against which subsequent coding and data can be compared (Glaser, 1978). Comparisons of the *properties* and *dimensions* of the core category provide information for the phenomenon under study accounting for variations of the basic social psychological process within and between participants (Glaser, et al. 2008/1967; Field & Morse 1985; Stern, 1980). An example of categories, properties and dimensions arising from this research can be seen in Appendices 3 and 4.

Theoretical coding for this research generated three main categories that described the BSPP for SA Boomer ACD decision-making as identified in Appendix 2. These categories and subsequent thematic stages of the BSPP listed in Appendix 5 will be described in-depth in Chapters Four, Five and Six.

As theoretical coding develops, *axial coding* occurs. Axial coding combines several properties, dimensions or codes between and across

categories (Corbin & Strauss, 2008; Glaser & Strauss, 2008/1967). The form of axial coding used in this research is representative of the original classical grounded theory approach but other forms of axial coding have also been used in grounded theory as described in the following section.

### *Axial Coding*

In describing how axial coding occurs, Field and Morse (1985) and others (Glaser, 2009; Corbin & Strauss, 2008) define it as the process of relating codes (categories and properties) to each other in both an inductive and deductive fashion until data saturation occurs. Glaser (2002) warned, however, that engaging in axial coding too soon or as a defined method in and of itself may compromise theoretical sensitivity and generate premature identification of the proposed BSPP. Glaser (2009; 2002) believed that for rigour to be achieved in development of the categories, core category and BSPP, accepting the data as it was without linking it to other theoretical positions situated the theory emerging from the phenomenon under study within its own context rather than others. To do otherwise could be detrimental to substantive theory development which by definition is about a particular context and time.

Axial coding in this research followed the primary intent described by Glaser and Strauss (2008/1967) in the original version of grounded theory. For this research study, this involved relating categories to develop more fully the properties and dimensions of each of the categories as described in Appendix 4 without other theoretical constructs being introduced at this level of coding as proposed by Glaser (1978).

Strauss (Corbin & Strauss, 2008) reconsidered the rigorousness of this approach and with Corbin, developed a different method of axial coding which incorporated other theoretical perspectives during the CCA process. This difference in the manner in which axial coding was used created two different schools of grounded theory, (e.g. *Classical Grounded Theory* and *Corbin and Strauss Grounded Theory*) and has since led to further variations of the grounded theory approach evolving from the Corbin and Strauss methodology.

Modification of the CGT method by Corbin and Strauss (2008) led to a split between Glaser and Strauss professionally and ideologically (Glaser, 2009; Stern, 2009; Corbin & Strauss, 2008; Charmaz, 2006; Walker & Myrick, 2006). This divide has since required researchers to identify which style of grounded theory they are using in their research, (e.g. CGT or other versions for clarity in theoretical development) (Morse & Richards, 2002).

This research study has used CGT in the manner originally intended to ground a sample of the SA Boomer experience of ACD decision-making to the context and time in which the research has been conducted. Conducting the research in this manner enables authentication of this sample of SA Boomers' experience as being their own at a time when they are not experiencing pressure to create ACDs in contrast to the conditions of ACD decision-making occurring for other groups previously studied. Conducting this research study according to the original CGT methodology also prevented muddling in data analysis. Muddling can occur when extrapolating subjective knowledge of a phenomenon based upon participant experience at the same time as interposing subjective interpretation of the phenomenon based on the researcher's experience or knowledge and can compromise the rigorousness of the substantive theory being developed (Walker & Myrick, 2006). This process of substantive theory development is further explicated in the section that follows.

### ***The CGT Theoretical Development Process and its Application in this Research***

Glaser (2009; 2002) argued that it was not until the BSPP had been identified that substantive theory development could begin (Glaser, et al. 2008/1967; Glaser, 1978). Morse and Richards (2002, p.57) suggested this was because theoretical development conducted in this fashion is *densely argued* because the concepts and relationships emerging from the data needed to be explored over stages and phases of the process without premature conclusions based on other theoretical positions.

The BSPP identified in this research represented the one core category of meaning running through all of the data to account for variations within and between data. The core category arising from this research was identified throughout the CCA coding process as well as in interview *memos*.

The creation of memos or field notes at the same time as data collection is an established social science research practice that was familiar to both Glaser and Strauss (Morse & Richards, 2002). In CGT however, memos became a way of incorporating a critical realist perspective of the societal constructs and processes that might be impacting on the behaviour or practice being investigated. Memos also established a clear audit trail of how interpretation of the data influenced subsequent data collection and eventual theoretical development. An example of a memo recorded for this research is provided in Appendix 6. This memo describes how one participant's knowledge and experience of ACDs influenced her consideration of them.

As coding resumes, memos should be revisited to re-establish theoretical sensitivity during subsequent analysis (Glaser, et al. 2008/1967). In many ways, memos provide the vital link between what the data offers and the interpretation of these offerings into substantive theory (Glaser, et al. 2008/1967; 1978).

Glaser and Strauss (2008/1967) advised that data generation, including memos, should continue until theoretical saturation occurred. At this point, the development of the substantive theory linking practice and behaviour would take over. When substantive theory was derived from this method, then it could be readily operationalised in empirical studies when appropriate or lead to more formal theory development (Glaser, et al. 2008/1967, p. 3). For the purposes of this research, memos were continued past the point of coding as seen in Appendix 7 to further delineate and confirm theoretical saturation and establish the BSPP.

By identifying the BSPP through the use of multiple methods such as coding and memos, trustworthiness of the data in this research study was enhanced. Lincoln, et al. (1985 cited in Morse & Richards, 2002) described that the trustworthiness of qualitative research data required establishment

of *credibility*, *transferability* and *consistency* of the data. Credibility was defined by Glaser (2008/1967) as a description of the phenomena such that both the scientist and the layperson could recognise and identify with what was being said. Transferability was met when concepts arising from the research were transferrable from one person to the next (Lincoln, et al. 1985 cited in Morse & Richards, 2002). Finally, consistency of the findings established that the results were dependable and represented similarity from one person to the next (Lincoln, et al. 1985 cited in Morse & Richards, 2002). Theory containing these elements constituted *fittingness* (or reliability) and *veracity* (or validity) of the data for the phenomenon being researched (Morse & Richards, 2002).

In determining the trustworthiness of the findings from this research, credibility was met through description of a BSPP recognised as a process each participant underwent multiple times and at multiple levels in ACD decision-making. Participants did not always acknowledge this process in a conscious manner but described elements of the process throughout their discussion of ACDs. This BSPP was identified from the data collected of all participants indicating the similarity of the process across the different groups of HCPs and LPs. Subsequent discussions of the BSPP with colleagues and lay people reiterated further that the identified BSPP was one recognised by anyone involved in ACD decision-making and resonated particularly for those who were of the Boomer generation.

The BSPP described in this research was deduced through CCA of factors or themes repeated from one participant to the next that described both meaning and action in ACD decision-making. Establishing that these factors were transferable and consistent between participants was done through the systematic use of interview questions exploring these factors as they arose from one participant to the next. These interview questions are listed in Appendix 8. Conducting the interviews in this fashion provided both fittingness and veracity of the data as theoretical sensitivity developed. This theoretical sensitivity was underpinned by the application of a rigorous method of participant sampling, data collection and data analysis. The next section provides a detailed description of this method.

### ***The Detailed Method of CGT Applied in this research***

A requirement of CGT is to develop an “initial, systematic” approach of data collection to generate theory from the data collected (Glaser, et al. 2008/1967, p. 3). The systematic approach used to explore SA Boomer ACD decision-making in this research is described in the sections that follow.

#### *Research Question*

The following research question “What factors influence ACD decision-making by Boomers in South Australia?” was established as the premise on which to conduct this research. Consideration was then given to preferred research methodology and method for answering this research question. The preferred methodology and reasons for this choice were described in previous sections of this chapter.

After establishing the methodology to use, the choice of method for data collection was considered. Interviews were chosen as they offered the opportunity for gaining in-depth information of factors influencing a sample of SA Boomer ACD decision-making; additionally, there was no logistical or practical manner in which to observe this phenomenon.

#### *Ethical Approval*

Before proceeding with participant recruitment and interviews, ethical approval was sought to conduct the research. The project was subsequently approved by the Flinders University Social and Behavioural Sciences Ethics Committee Project No. 4036 as evidenced by Appendix 9. Ethical conduct of this research followed the principles established by the Flinders University, Social and Behavioural Ethics Committee as well as the Australian Government National Health and Medical Research Council (Flinders University, 2011; National Health and Medical Research Council - NHMRC, 2007). These principles included, but were not limited to; informing participants of the reason and parameters of the research study, gaining their formal consent, enabling them to withdraw from the study at any time without prejudice, providing them with a place and time of

interview of their choice, as well as provision of the details of those who could be contacted to register complaints about the research.

Volunteers who successfully met inclusion criteria for the research were asked to nominate a place and time for interview. Additional information about the research was then posted to participants, including consent forms for audio taping to be returned at the time of interview. Pseudonyms were applied to the returned consent form prior to transcription to protect the anonymity, privacy and confidentiality of information received. This de-identification process occurred throughout all transcription and reporting phases of the research.

Consent forms and other paperwork as well as computer-based information were and continue to be assessable only by the researcher and her supervisors. Hard copy transcription information and forms are held in a secured file cabinet in a secure room in accordance with NHMRC (2007). Audio taped material was secured on a password-protected computer with interviews on the audio recorder deleted once transfer to computer was completed.

Participants were reminded prior to and during interviews that any information that they did not want recorded would not be recorded and the interview would be stopped at their request if the information provided was deemed to be of a sensitive nature. The subject matter of ACDs necessarily invokes discussion of sensitive issues such as the manner of someone's death. In recognition of this, additional suggestions for participants to seek the support of others after the interview were made. These supports included provision of a pamphlet with additional information about ACDs as well as the suggestion that participants nominate a person prior to interview available for them if they found afterwards that the interview process engendered discomfort or distress.

### *Recruitment of Participants*

Recruitment of participants was based on inclusion criteria previously identified as consisting of; *age* – the person had to be born between 1945 -1965 to represent the era described as the Boomer generation, *knowledge* – the person had to know something about ACDs, either



through recognition of the instruments or their purpose though extent of knowledge was not a factor in selection, *living arrangements* – the person could not be living in an institutional setting where ACDs were a requirement of entry as this pre-empted other factors for consideration of ACDs, and *language* – the person had to be able to speak English to a level of understanding which could convey their experiences and considerations of ACDs. Appendix 10 is an advertisement for participants and included the criteria for participation in this research.

Placement of advertisements for recruitment of participants considered the greatest opportunity of recruitment as well as keeping recruitment as open as possible. Subsequently, advertisements were placed in both a southern metropolitan Adelaide university and hospital where visitors and employees of these facilities with some knowledge of ACDs could see the advertisements. Choosing the southern metropolitan Adelaide area was convenient and deliberate as the public within this location had less exposure to coordinated ACP policy being promoted throughout other areas of Adelaide at the time of interview. Choosing participants from this locale also provided a starting point to measure the influence and effectiveness of ACD completion through ACP promotion as proposed by the SA Department of Health (SAG, 2009b).

Prior to interview, volunteers were screened by telephone to assess their suitability according to the inclusion/exclusion criteria for this research. Several potential participants were actually excluded from participation through this process either because they were outside of the age range (2 people) or did not have an understanding of what an ACD was (1 person).

Initially, it was expected and intended that the majority of volunteers would be lay people (LP). It was presumed LPs would have more experience with ACDs through acting as SDMs for others. Healthcare professionals (HCPs) or hospital personnel were not excluded from participation and, indeed, became the majority of the sample recruited. It was not anticipated that HCPs would volunteer for this research as it was presumed that their exposure to ACDs would be commonplace and therefore not generate interest for participation. Instead, it was later

revealed that their experience as HCPs as well as acting as SDMs for others influenced their ACD decision-making to such an extent that they used this research as a means for exploring decision-making of ACDs for themselves.

Participants were also accepted through *snowballing* (mentioning of the research through friends and colleagues to others) at workshops and seminars on ACDs or ACP. Participants gained in this manner were acceptable and within the parameters of ethical approval because participants were being purposively sampled for their knowledge about ACDs and pre-screened for this knowledge, thus no bias was inherent in the snowballing process.

Originally, no cut-off point was made for the number of participants to interview and, unexpectedly, over the course of the twelve months of the interview process, twenty people offered to participate in this research. However, due to constraints of time and development of data saturation, data collection ceased after the seventh consecutive person that volunteered was interviewed (n=7). Those participants who were not able to be interviewed due to time restrictions of this research were contacted and provided with advice and information about advance care directives in lieu of participation.

### *Setting*

As recruitment of participants was conducted throughout the Adelaide metropolitan region, the setting for this research included multiple locations within this region as well as a rural setting associated with one of these locations. These locations included a university campus and several places of employment, (e.g. acute care, mental health facility, and rural educational environment). Of the seven interviews conducted, four were performed on the university campus and three at the participant's place of employment at the request of the participants. Participants from a rural location were included in this study for two reasons. Firstly, because conditions of their employment included the southern metropolitan Adelaide region, thus they had experience with ACDs from both a metropolitan and rural perspective. Secondly, the rural participants were

also part of a deliberate purposive sampling strategy since some of the participants interviewed in the earlier stages of the research related experiences about ACDs from a rural perspective.

### *The Interview Process*

All interviews were audio taped and transcribed verbatim by the researcher. Interviews were conducted between June 2008 and January 2009. Memos were recorded immediately after the interview was completed enabling theoretical sensitivity for subsequent interviews as well as an audit trail for revisiting elements of theoretical development as time progressed.

The interview process was conducted with a systematic approach using the same open-ended question for all participants asking them about their experience with ACDs. If additional information was required the first question was followed by four pre-established prompt questions to enable further elaboration of ACD decision-making by the participant. These prompt questions were developed from knowledge in the literature about ACDs as well as information from the South Australian Advance Directive Review (SAG, 2008b). This method of interviewing was developed by the researcher in conjunction with CCA. The CCA process used the same open-ended question for each interview as well as the additional four prompt questions and then initial prompt questions were supplemented with more questions about factors arising from within one interview to be tested in the next. Questions not asked at earlier interviews were assessed against transcripts from earlier interviews for information relating to these questions. All interviews were established as having information relevant to the 18 questions asked in the final interview. An example of the method of development of these open-ended, prompt and additional prompt questions can be seen in Appendix 8.

Interviews conducted lasted between sixty and ninety minutes although most participants were happy to continue longer. Due to concerns about the effect of discussing sensitive issues raised during the interview and possible delayed psychological and emotional effects that might occur, most interviews were terminated within the time period

described to reduce stress to the participants and the researcher. This also provided the researcher adequate time and opportunity to reflect on the information arising from the interview and complete memos.

All participants sought additional information on ACDs either during the interview or afterwards. When participants requested this information during the interview, they were politely informed that it could not be discussed during the interview but would be happily discussed at the conclusion of the interview. This procedure was necessary as the object of this research was not to inform the participants about ACDs, but to understand their current knowledge of ACDs from their own perspective unbiased by the research process. In anticipation of participant requests for more information about ACDs, prior to the first interview a pamphlet was created by the researcher with details of facilities that could assist participants with any questions about ACDs. Pamphlets were only distributed at the conclusion of each interview to prevent this information from influencing participant understanding and knowledge of these instruments.

When interviews were concluded, they were transcribed verbatim by the researcher as soon as practicable after the interview. This transcription process developed theoretical sensitivity for the coding process and data was coded in accordance with the CGT approach in the manner described previously. Throughout data collection, transcription and coding, the process of CCA was used to establish data saturation. When data saturation was identified, the BSPP was defined and the theoretical construct of the behaviour and practice of SA Boomer ACD decision-making was developed as seen in Appendix 4.

The preceding sections of this chapter have described in detail the manner in which CGT was used to answer the research question “What factors influence ACD decision-making by Boomers in South Australia?” In doing so, this chapter sought to substantiate the trustworthiness of the findings that will be discussed in subsequent chapters. It is acknowledged however that there were several limitations to the conduct of this research and these limitations are discussed in the following section.

### ***Limitations of This Research***

The first limitation identified in this research involved participant selection. Participants involved in this research study were drawn from one section of a large metropolitan region in South Australia. Classical grounded theory describes and is derived from specific contexts, so it is possible that participants from this area may have different perceptions and experiences of ACD decision-making to participants from other areas of the metropolitan site studied as well as other areas of Australia. Different perceptions to ACD decision-making may be influenced by socioeconomic and cultural perspectives. Participants in this research were tertiary educated and all were of Caucasian/Australian heritage; therefore, findings of this study may only be relevant to participants from these sociological viewpoints.

A second limitation of this study was that five of the seven participants were HCPs. This was neither sought nor anticipated but the LP perspective is not as adequately represented as was originally intended; as such, HCP knowledge and experience of ACD use may not reflect LP experience and any differences defined between HCP and LP perspectives are speculative at this stage. However, it is important to note that the majority of HCPs had experience with ACDs as family members in addition to their employment experience indicating both a HCP and LP perspective.

Third, CGT requires purposive sampling of similar participants in a similar context over a period of time for true data saturation to occur with theoretical confidence. As this research could not be conducted in such a controlled manner, it is acknowledged that information derived from this research constitutes a preliminary step in the process of testing the core category for substantive theory on this phenomenon. This is consistent with CGT methodology which dictates that substantive theory development of a phenomenon is established over time.

## **Summary**

This chapter has described the methodological approach chosen to answer the research question “What factors influence ACD decision-making by Boomers in South Australia?”

The qualitative methodology chosen as being most suitable for generating this ontological perspective was classical grounded theory or CGT. Classical grounded theory was defined as being more suitable than other qualitative methodological approaches because it combined subjective understanding with a rigorous approach to theoretical development to explain the meanings and actions of this particular demographic group’s experience of the phenomenon being studied. The methodological approach of CGT described in this chapter included description of open, purposive and theoretical sampling of participants as well as the process of constant comparative analysis (CCA). The CGT methodology for participant sampling was discussed in parallel with data collection and analysis using the CCA approach to establish methodological relevancy of the findings from this research.

Constant comparative analysis as used in CGT during transcription, coding and theoretical development was also described. Description of this process highlighted the elements of trustworthiness of qualitative data to be met in this research. Trustworthiness of qualitative data was defined as credibility, transferability, and consistency of the data such that findings from the data fit and could be verified by others. Identification of fittingness and veracity was defined through the coding process of CGT.

Two types of coding were described as being used in this research. These two types of codes; *in-vivo* and *substantive* were used throughout the process of *open, substantive or theoretical* and *axial coding*. Examples of these codes and the process of coding conducted in this research were provided through Appendices 2 - 5. Particular mention was made of axial coding as this form of coding was reinterpreted in later years by one of the originators of CGT, Strauss that subsequently led to a division between him and Glaser as to the preferred method for conducting CGT research. This division has since necessitated that subsequent researchers identify

the type of grounded theory being used in their research. This research has used the Classical Grounded Theory approach.

Coding in CGT produces theoretical sensitivity and the process of theoretical sensitivity was described in correlation with participant recruitment and data saturation. Data saturation was identified as being achieved in CGT when no new information was forthcoming. For this research, data saturation was achieved by the seventh interview. In CGT, when data saturation has been reached, categories or themes defining the meaning and actions of the behaviour and practice being researched are then developed. Multiple categories developed in CGT are then integrated with each other to identify the core category and BSPP or basic social psychological process explaining the behaviour and practice being researched. After the methodological process of CGT was discussed, the actual method of CGT used in this research was then described. The description of this method included ethical considerations, recruitment of participants, setting, the interview process and finally, limitations of this research. The core category and stages of the BSPP derived from this research are described in the next three Chapters Four, Five and Six beginning with Chapter Four, which describes demographic information about participants and the first stage of the BSPP.

## **Chapter 4 - Identification of the Factors Influencing ACD Decision-making by SA Boomers – Part A**

### **Stage 1 - Contemplating Knowledge**

This chapter describes the first stage of the basic social psychological process (BSPP) of ACD decision-making by SA Boomers. The chapter begins with participant demographics and a description of the theoretical development of the findings that follow. These findings express and are indicative of the BSPP identified for this research. Findings are described as themes representative of categories emerging from the CCA process. Findings are then integrated with relevant literature to discuss the implications of these findings in relation to Boomer ACD decision-making and the BSPP. The BSPP identified from this research was that of contemplation. Contemplation describes the behaviour of participants at every stage of their ACD decision-making process and was a necessary behaviour for participants to engage in as it provided time to assess the necessity and consequences of ACD creation. Contemplative stages were not linear but were entered into depending on the context in which contemplation took place.

The three chapters that follow have been structured to report the stages of contemplation that took place as follows:

- Chapter Four: Stage 1      Contemplating Knowledge
- Chapter Five: Stage 2      Contemplating Relationships
- Chapter Six: Stage 3      Contemplating Actions/Inactions

Contemplation was associated with the context of participant experience of ACDs and decision-making was formed through either their employment as HCPs, as family members or as general members of the lay public (LP) exposed to these instruments. This chapter, Chapter Four, discusses the first stage of this contemplative experience, *Contemplating Knowledge*. Knowledge was developed on multiple levels and influenced by individual context and characteristics of the participants. Characteristics that personify this context are described in the next section through discussion of participant demographics.



### ***Participant Demographics***

Of the seven participants interviewed for this research, two were male and five were female. Five of the participants lived and worked in the southern metropolitan region of Adelaide at the time of interview. One of the participants worked in the southern metropolitan region of Adelaide as well as in a northern rural area of Adelaide. Another participant lived and worked only in the northern rural area of Adelaide but frequently visited the southern metropolitan Adelaide area for healthcare so was also included in this research. All participants were born between 1945 to 1965 (aged 43 to 61 at time of interview) meeting the inclusion criteria of being born within the time designated as the Boomer generation. Of the seven participants interviewed, five identified as healthcare professionals with employment across a variety of healthcare settings including; acute care, residential aged care and mental health (Mr Z, Mr X, Ms C, Ms D, Ms E). Two participants identified as carers for family members though this did not constitute their employment (Ms B, Ms F). One person's employment was ill-defined so this participant was subsequently described as a lay person (Ms B) whilst the other nominated layperson worked as an administrative assistant in an educational facility (Ms F). All had a minimal educational level of at least high school education or its equivalent. Five of the seven participants had healthcare professional degrees established from either the tertiary system or hospital-based training.

The interview process described in Chapter Three enabled participants to expand upon the answers to the questions posed to explain the reasons behind their answers. In doing so, participants revealed other aspects of their characteristics relevant to ACD decision-making. These other influential demographic characteristics are discussed in the following paragraphs.

All of the participants had experience as SDMs for others either in a professional or personal capacity. Participants' completion of ACDs for themselves however was less clear and the reasons for this are described under the thematic heading "*Talking about the same thing*". Nonetheless, data analysis of the transcripts concluded that four of the seven

participants (Ms C, Mr Z, Ms E and Ms F) had indeed completed or were going to complete one of the three instruments recognised as ACDs in SA (EPG, MPA, Anticipatory Direction). Other participants (Mr X, Ms B, Ms D) had completed either an EPA, a Will, or nothing at all.

Discussion about completion of ACDs generated comment on substitute decision-makers or SDMs and led participants to describe the composition of their families. There were a variety of familial contexts described as illustrated in Appendix 11. The context of family composition was a critical consideration for participants developing knowledge of ACDs as well being able to move onto the second stage of contemplation described in Chapter Five, *Contemplating Relationships*. The composition of the family units of participants included: two divorcees with children (Ms C and Ms D), one partnered without children (Mr X), three with spouses and children (Mr Z, Ms E and Ms F) and one (Ms B) who was single without children.

No demographic information was collected about culture but subsequent data analysis indicated that no participant identified themselves as coming from another country, race or ethnic group other than European Australian. One participant (Mr X) identified that his partner was from a different country and culture.

All participants experienced one or both parents with varying levels of morbidity and mortality. With regard to parent-child relationships, two participants identified themselves as adopted children (Ms C and Ms F) and indicated that this influenced their ACD decision-making.

All participants mentioned siblings and relationships with siblings when expressing factors influencing ACD decision-making, especially in the second stage of contemplation, *Contemplating Relationships*. Sibling relationships were identified as important to consideration of SDMs not only for others but also for the participants. This type of demographic information provided additional context to ACD decision-making and assisted the theoretical development of the BSPP.

The theoretical development process used to incorporate participant characteristics with findings and the literature is described in the following section.

### ***Theoretical Development of Findings***

Theoretical development of this research began by drawing together categories illustrating different stages of contemplation of ACD decision-making. The first stage of contemplation comprised the categories of knowledge, awareness and experience as well as the properties and dimensions of these categories and their importance important to the initial phase of ACD decision-making. Therefore, this first stage has been called *Contemplating Knowledge*.

Having some form of knowledge of ACDs was necessary for participants before contemplation of ACDs could begin. The forms of knowledge most often identified by participants in their contemplation of ACDs were awareness and experience. David Hume, a 19<sup>th</sup> century philosopher, suggested that the way to critically understand human behaviour was to recognise concepts about a person's life based on their past experiences (Hume, 2005). This was because before a person can make a decision about how to act on something, they consciously or subconsciously need to incorporate past and present knowledge in a way that provides a context within which to contemplate the appropriate action to take (Pearsall & Trumble, 1996). This type of knowledge is referred to as *experiential* knowledge – a philosophical perspective which dictates that knowledge can only be gained through experience and not prior (*a priori*) to experience (Pearsall & Trumble, 1996, p.493).

In illustrating an example of how experiential knowledge influenced behaviour, Kitwood (1993; 1997) identified that when people experience a person with dementia, a recognition of the twin fears of mental instability and death results. This experience may then create avoidance behaviour with other people who have dementia to prevent the re-arousal of fear induced by the previous experience. The person acting in this fashion has established a behaviour and practice based on experiential knowledge.

Participants in this research expressed their experiential knowledge of ACD decision-making based on what they observed of others who were subject to these instruments. The manner in which participants expressed this knowledge was through the use of phrases such as 'I think', 'I know', 'I

assume', 'I'm aware' and 'I saw'. These phrases indicated knowledge could be gained by either direct or indirect means.

Awareness and observation are defined as 'knowing, cognisant and informed' and 'being watchful' (McKechnie, 1979a and c, pp 131 and 1235.) implying the experience of active agency of the effects of ACD use on others initiated participant contemplation of ACDs for themselves, as illustrated by Ms D:

*it's best to get something in place so while you also have...you're cognitively intact to do it...oh, look, it's that, it's just getting older...just because of my own mortality **I think** about it in relation to me...this realisation that you can depart this earth any tick of the clock...If you're looking at advance care directives you don't have to look at the fact that you're going to die, you can look at the fact that you might be incapable of making these decisions for yourself at some time (Ms D)*

Ms D's statement identified that her experiential knowledge of ageing was a factor influencing her contemplation of ACDs. The ageing process was an active agency process experienced not only by Ms D but also by others. Ms D became aware that as she grew older she, too, was going to be vulnerable to mental instability and death just like the person with dementia described by Kitwood (1993; 1997). If that were to be the case, she expressed the thought that she should do something about it. In acknowledging this awareness, Ms D united the vulnerabilities inherent with ageing to the practice of ACD decision-making and assimilated knowledge and behaviour with actions and consequences.

### ***Behaviour and Consequences***

A theory developed by Glaser and Strauss (1965, p.1) called *the awareness context* described how awareness of behaviour and consequences influenced actions and knowledge. The context illustrating this theory was described as an awareness of dying (Glaser, et al. 1965). Awareness in this context comprised knowledge about the dying state of a patient in hospital. This knowledge was developed through the behaviour

and practice of others (family, patients, and healthcare professionals) towards the dying person.

According to the awareness context theory, when imminent death of a person in hospital was not acknowledged, psychological processes, (e.g. denial), created social consequences that prevented the appropriate support, care and decision-making required for the dying person.

Participants in this research acknowledged that the concept of dying was important in their contemplation of ACDs. This was illustrated by Ms D's identification that death could happen at any 'tick of the clock'. On the other hand, dying was not the only time when preferred care or decision-making could be compromised. Ms D recognised that cognitive impairment, too, could prevent personal autonomy in decision-making so the awareness context of participants in this research extended beyond dying to include the future death of self and others through ageing processes that would impair cognition.

By identifying cognitive impairment as another state in which personal autonomy in decision-making could be compromised, participants revealed their knowledge of the unintended consequences of prolonged life. Boomer generational awareness and knowledge of the impact life-prolonging technology can have on personal autonomy, especially for the cognitively impaired, was also described in the literature as evidenced in Chapter Two by Kaplan, (2009) and others (Rubin, 2007; Gillick, 2006). The literature revealed that promotion of medical technologies extending life required this demographic group to consider not only the future healthcare and welfare they may want as they age but also when death would be preferable if cognitively impaired (Metlife Foundation, 2011). Ms D's comments incorporating both of these elements of awareness linked her societal experience of ageing to the psychological contemplation of protecting her preferred QOL through the use of ACDs.

Participants such as Ms D recognised that the appropriate behaviour to ensure autonomy in future decisions about healthcare and welfare when dying or cognitively impaired would be to create ACDs. However, awareness and knowledge alone were not necessarily enough to engender completion of these instruments as illustrated by the phrase

every participant in this research used to describe their contemplative process: “I know I should, but I haven’t”.

The difficulty for people to translate this knowledge into practice was reflected empirically in the literature which described low uptake rates (15-20% on average) of these instruments in countries where ACDs have been legislated, (e.g. Australia, UK and USA) (Fargerlin, et al. 2004; HHR, 2004; Collins, et al. 2006; Lynn & Teno, 1993).

To understand the BSPP required for translating knowledge of ACDs into creation of them, Morse’s (2006) research described a four-step process that Boomers needed to undergo before completion of ACDs could take place. The model proposed, LAMP, consisted of limited, activated, motivated and perfected awareness (Morse, 2006). *Limited awareness* comprised knowledge of ACDs as superficially conveyed through advertising or education. *Activated awareness* was the next stage developed as Boomers experienced ACD use and implementation. *Motivated awareness*, the third stage, engaged consideration of how ACDs could be useful to the Boomer; whilst *perfected awareness*, the final stage, was reached when Boomers actually completed ACDs for themselves (Morse, 2006). South Australian Boomer participants in this research engaged similar levels of awareness as evidenced through phrases they used to describe their contemplative process such as; ‘I knew’ (limited awareness), ‘I saw’ (activated awareness), and ‘I realised’ (motivated awareness). Perfected awareness as occurred in the Morse (2006) model was demonstrated only by participants in this research who completed ACDs.

Though these levels of awareness may indicate similarity between US and Australian Boomers of the need for ACDs, the societal context of this awareness differed greatly. In the US, there was a targeted and organised promotion of the US version of ACDs through the Patient Self Determination Act (1990). Promotion and legislation supporting ACDs meant that respect for personal autonomy in the healthcare environment in the USA has been enforceable and if ACDs are not enacted, prosecution of the responsible parties can take place, (e.g. wrongful living suits (Tucker, 2009; Lynch, et al. 2008)). In contrast, enforceability in the

Australian context may be variable between jurisdictions (Brown, et al. 2009; Brown & Jarrad, 2005b; OPASA, 2003). For example, the 2009 NSW Supreme Court Case of Hunter and the New England Area Health Service v A (2009) confirmed that ACDs were legally binding under the Common Law and therefore to treat against expressed wishes constitutes assault under the Common Law throughout Australia *except* when statute law has overturned the Common Law (McDougall, 2009). The different legislation context in Australia has meant that the incentive for those in the position to do so to enact, complete or promote these instruments is substantially more reduced. Nevertheless, as participants in this research revealed, the lack of legislative incentive to complete ACDs had not stopped the public from contemplating protection of their future autonomy through ACDs.

Contemplation alone however was not enough for participants in this research to initiate completion of ACDs. Other factors enhancing knowledge and awareness of these instruments were needed to continue the momentum for further contemplation and eventual action. These other factors are described in the sections that follow.

### ***The Ageing Process***

The reference by Ms D to 'getting older' suggested that a factor influential to ACD decision-making was the knowledge that participants were ageing. Kahana, et al. (2004) found that consideration of one's own mortality typically increased as one aged but discussions did not. Kahana, et al.'s (2004) research found that younger age was associated with having more discussions about end-of-life (EOL) though the discussions did not correlate with actual recording of preferences. Ms E illustrated how thinking did not always lead to actions as she described the way the ageing of her family influenced contemplation of ACDs for herself:

*My oldest is 14 and we should really have done it 14 years ago...My step-Mum's 67,68 with Alzheimer's, my Dad's 80...you've got me thinking in fact that I should be doing mine now (Ms E).*

As demonstrated by Ms E, although the Boomer demographic is not yet typically experiencing the frailties of old age or terminal illness often associated with ACD creation, nonetheless they are aware that others they love are. This contemplation of their family ageing initiated conversation by participants about the age they felt was most appropriate for healthy people to engage in ACD creation. Participants nominated 40 to 50 years of age as being an appropriate time to consider ACDs, yet studies conducted on ACD use and consideration have concentrated on those aged 65 years of age and older (Silveira, et al. 2010; Teno, et al. 2007; Wilkinson, et al. 2007). This mismatch between when ACDs should be considered and the emphasis of research investigating ACD use in older cohorts has created discontinuity for evaluating effectiveness of these instruments in younger and healthier age groups.

Participants in this research identified younger ages for ACD contemplation because of their experience of chronic and terminal illness of people at younger ages. This experience correlated with evidence from the literature suggesting that the Boomer generation and those that follow will experience chronic and terminal illness much earlier than 65 years of age (ABS, 2010a;2003). This means that ACD decision-making will be necessary at earlier ages than has been emphasised in the ACP programs studied in the literature (Detering, et al. 2010; Bravo, et al. 2008; Wilkinson, et al. 2007; Jezewski, et al. 2007). The factor of chronic illness at a younger age necessitating an ACD was acknowledged by Mr Z who indicated that if ACDs had to be made during a time of sudden and debilitating illness, some people would not be able to consider creating them at the time required:

*I remember being in a state that would require an advance directive, I wasn't really in a place to do it  
(Mr Z)*

This level of awareness as demonstrated by Mr Z elevated his *limited awareness* stage described in Morse's (2006) model to the next stage of *activated awareness* as his general knowledge was transcended into a personal context. Evidence that younger demographic groups appreciated the need for ACDs at younger ages supported the original intent of these



instruments to be used by those 18 and older, not just those who were very old or dying (Hickman, et al. 2005; OPASA, 2003; PSDA, 1990).

Knowledge of the benefit that could be had in completing ACDs at earlier ages proved paradoxical however for some participants such as Mr X who contemplated:

*It comes back to thinking about it at a time when there isn't almost a need to think about it, yeah, having time, a time to consider (ACDs) (Mr X).*

The paradoxical nature of the best age to create ACDs indicated that although participants in this research were aware they were getting older and ACDs should be completed as soon as possible, other factors were needed to actually force them into doing something about it. These other factors included direct experiential knowledge of the utility of these instruments not only for themselves but for others. This experiential knowledge was often gained through participant employment as a HCP or in the role of SDM.

### ***Meeting the Needs of Others as an HCP or SDM***

Literature on the use of ACDs has described the impact of ACD decision-making on HCPs (Salmond, 2011; Denier, et al. 2010; Brown, et al. 2009; Reuben, 2009; Heyman, 2008; Black, 2006; Borbasi, et al. 2005; Brown, 2002). Though these instruments were designed to protect the patient, it was the HCP that bore the brunt of the consequences of patient or SDM decision-making. This reality may have explained, in part, why HCPs volunteered in greater numbers for this research.

An example of how HCP participants used this experiential knowledge in their own ACD decision-making was provided in the previous example by Mr Z when he described needing ACDs at a particular time but not being able to do so. This implied that, at that time he required the assistance of someone else who could make decisions for him. His activated awareness of the need for an SDM to make decisions on his behalf was influenced by his direct experience as a social worker involved in the creation of ACDs for others. Mr Z's employment in this field provided him with the opportunity to both learn about and ascertain the timeliness of

these instruments not only for himself but also for members of his family, as he explained:

*Because I'm experienced in a couple of ways ... (When) Dad reached a stage where he couldn't sign it (ACD) then I knew that there'd be other complications once he's reached that point (Mr Z).*

The knowledge provided by Mr Z's professional and personal experience gave him an advantage for assessing utility of these instruments. This advantage was then reinforced when he acted in the roles of HCP and family SDM. The elevation of knowledge to an appreciation for applicability of ACDs was described by all participants in this research who were HCPs and who had also acted as family SDMs (five of seven participants).

The literature indicated that research on the HCP family experience of ACD decision-making is increasing (Durbin, 2011; Salmond, 2011; Wendler & Rid, 2011; Nolan, et al. 2009; Chan, 2004). Durbin (2011) and Wendler & Rid (2011) found that SDM decision-making became an imposition when families were not aware of or clear about the value preferences of the person they were representing and there was pressure by other family members to make decisions that overrode previously written or verbal preferences. When this situation occurred, it put HCPs in conflict with families who requested decisions that were contrary to previously stated patient requests (Salmond, 2011). The awareness of the distress this could cause for HCPs, SDMs and family members was further emphasised if the HCPs experienced such situations themselves in their own families (Ruff, et al. 2011). Ms E, a HCP participant in this research described how her mother's personal experience of SDM decision-making affected her own contemplation of ACDs:

*Mum ...had been through similar things with her parents without any direction...the experience she portrays was quite horrific as a daughter because she knew that Grandpa wouldn't want some things to happen...it did make us probably a lot more aware of what could happen to our kids if something happened to us (Ms E).*

Adverse events experienced by others through lack of ACDs were frequently described by participants in this research in the context of parent-child relationships as illustrated by Ms E. The parent-child relationship created a twofold approach to contemplation of ACDs; not only were participants contemplating ACDs in relation to themselves but they also contemplated them in relation to other family members. Morse's (2006) model contended that this level of awareness, *motivated awareness*, could be the precursor for completion of ACDs. This was not the case for all participants in this research however. Though they may have attained this level of awareness through others, it was not necessarily enough to promote the completion of ACDs for themselves. Additional factors which motivated participants to continue contemplating ACDs included those arising from participant engagement with the healthcare system.

### ***Experiencing the Healthcare System***

The impact of observing decision-making processes in the healthcare system created both positive and negative knowledge of ACDs for participants. Negative ACD knowledge was generated by observing or being aware of the consequences for patients of unclear or poorly informed ACD decision-making. Healthcare professionals, such as Ms E, expressed this knowledge in the following manner:

*I know that if you're working on the wards...you've been exposed to those decision-making processes a lot more...we've seen a lot of these things that can go wrong and families get destroyed by these decisions and these crisis situations...we're trying to avoid our children being in that situation and on a personal level, I'm trying to avoid being in it as a result of my parents (Ms E).*

Knowledge based from within the healthcare system of the consequences to families of poor decision-making was a motivating factor for participants' subsequent creation of ACDs for themselves and/or their

parents. This provided HCPs with an advantage for understanding the utility of ACDs over those not employed in the healthcare system.

Wendler and Rid's (2011) and Deep, et al.'s (2008) research suggested that for family SDMs without a healthcare background being unsupported or poorly informed about the decisions to be made increased the burden of anxiety and guilt felt by SDMs placed in these situations. These negative feelings were alleviated when SDMs were supported in their decision-making with clear ACDs (Wendler & Rid, 2011). Ms C expressed her concerns about how the public without knowledge or guidance to engage in ACD decision-making generated unrealistic and unsustainable expectations of the healthcare system:

*The hospitals are full. The availability of staff is not always there... (One patient) we have had in our hospital for the whole of this year...We have many frequent fliers...particularly if they live on their own...they want to live forever...'no, no, I want you to do everything to save my life'...we need to get them to see what reality really is because the system is clogged with people like that (Ms C)*

The consequences observed when the healthcare system was inappropriately used were also observed by LPs of this research, typically as a result of their engagement with the aged care system. Lay participant concerns centred on provision of healthcare resources as demonstrated in the following comments by Ms B:

*It's probably got a lot to do for me having less and less confidence in our health care system...I'm talking about as a consumer of the healthcare, of the aged care system...goodness knows what the healthcare system with less and less resources (will be like)... the public aged care has disappeared completely (Ms B).*

To alleviate the burden on both the healthcare system and those acting within it of poor, contradictory or conflicting decision-making, the literature described the importance of communication of patient values and preferences with the SDM prior to enactment of ACDs (Propp, et al. 2010; Barbour, et al. 2009; Kaldjian, et al. 2009; Deep, et al. 2008; Black, 2006).

When this communication was not evident, Mr Z offered the following insight into what could occur:

*(Without ACDs) it becomes long and drawn out and in the hands of the government (Mr Z)*

To prevent such an occurrence, participants in this research indicated that they were frequently called upon to assist either their own or other families to have discussions about EOL and ACP. A frustration identified by participants in having these discussions was lack of clarity in what a person wanted as well as the contentious nature of trying to elicit this information. Though having the discussion could be difficult, participants described that timing of the discussion could negate these difficulties and was important to consider when engaging a person in discussion of ACDs. There have been many programs described in the literature to assist HCPs to conduct these conversations (Propp, et al. 2010; Austin Health, 2006; Black, 2006). One such program, Respecting Patient Choices® (2008) has been implemented throughout Australia and several participants expressed their knowledge of this program. The program instructs HCPs on good communication skills for ACD discussions (RPC, 2008). Good communication of values and preferences for QOL generated positive experiences of ACD decision-making for participants. The skills required to produce good communication on this issue were described by participants in the section that follows.

### ***Being the Communicator***

Participants who experienced best practice in conducting ACD conversations were able to identify particular positive communication skills used in conducting these conversations as illustrated by Ms C:

*We do have one doctor who is Indian, he is just the most loving, caring man who sits down, and who captures the patient and discusses with them what he thinks is going to occur in their illness...he will always get a directive from the patient and that is such a good thing (Ms C).*

When these skills were observed, participant knowledge of the acceptance and respect for a patient's autonomy was reinforced. Brown

(2002) and others found that if medical practitioners did not communicate with their patients about ACDs or EOL, inappropriate medical treatment for patients resulted in diminished trust in the healthcare system (Grogan, et al. 2009; Berger, et al. 2008; Deep, et al. 2008). Poor or lack of communication on ACDs by medical practitioners was found to arise from bias against discussions about death or dying and poor knowledge of prognosis of different illnesses (Hancock, et al. 2007; Layson, et al. 1994). Participants in this research often mentioned that when they witnessed poor communication of ACDs, families and HCPs were left in conflict creating moral distress for the HCPs involved (Repenshek, 2009; Enes, et al. 2004).

Nevertheless, when participants in this research observed good communication on ACDs, as illustrated by Ms C, this generated a positive experience for contemplation of ACDs for the participants. Reflection on positive ACD discussions observed resulted in participants being able to conduct discussions with others that were compassionate, empathetic and respectful as evidenced in the following exemplar:

*(when discussing with a nursing colleague whose father was in intensive care) I did sit with her and talk to her about decisions that she (nursing colleague) may need to make very shortly because I've worked in emergency care...so I've actually seen that nurse since and she thanked me for discussing that with her (Ms C).*

Positive feedback such as that expressed by Ms C created experiential knowledge that reinforced the benefits of assisting others in ACD decision-making. Such feedback created more willingness by participants to enact this knowledge by having ACD discussions with their own family members.

All participants in this research also described that ACD discussions inevitably, and of necessity, generated a discussion of the values important to those having ACD conversations. These values typically identified elements nominated by a person as being important to their QOL. Quality of life was one of the most influential factors underpinning participant knowledge for ACD contemplation. Participant contemplation of

QOL centred on the need to ensure that the QOL they expected was not compromised by the value systems of others.

The motivation to protect their QOL was connected to participant observation and knowledge of medical practitioners' encouragement to others to live as long as possible. As Ms C indicated in a previous comment, extension of life over QOL gave the public false expectations of what they could expect from the healthcare system and frustrated both HCPs and some LPs in this study.

The promotion by others of the ideal that living longer should take precedence over QOL was seen by participants to be reinforced through the media in healthy ageing messages which minimised or obfuscated the reality of ageing and illness. These observations were also substantiated in the literature as well as consequences to the public of such an approach, (e.g. unrealistic expectations of successful CPR) (Hillman, 2010). Participants in this research with professional and personal experience of the healthcare system understood that the ideal of living longer was not representative of the state of care possible in today's healthcare and aged care environment and therefore was untenable. Participant knowledge was such that they understood the ideal of living longer came at a cost to QOL, especially as the dying trajectory in complicated illness states increased. The impact of illness on QOL as experienced by participants is discussed under the following theme.

### ***Understanding Illness***

In the literature, HCPs especially those treating people in ICU or with chronic illness were found to understand the real cost and burden of care of life-sustaining treatments on patients, families and the healthcare system for people with long and debilitating illness (Hillman, 2010; Camhi, et al. 2009; Reuben, 2009; Rood, 1996). Particular illnesses that participants in this research identified as requiring early ACD discussions were those of dementia and motor neurone disease (MND). These illnesses specifically were recognised by both HCP and LP participants as illnesses where personal autonomy could be compromised, as demonstrated in the following comments by Ms B:

*I think dementia is a huge fear...if you're one of the ones that get dementia...'cause it's the worst thing that can happen if you lose your mind...Motor neuron disease (also) does confront you because you lose, you don't lose your mind, but you lose everything else (Ms B).*

Much of the emphasis in the literature has been on the role of ACDs for the person who has dementia (Cartwright, 2011; Enck, 2010; Access Economics, 2009; Hughes & Baldwin, 2006). This has been because this disease has a long dying trajectory and, as indicated by Kitwood (1993; 1997) generates anxiety for those who see their own future through the eyes of a person with dementia. Compounding this knowledge is awareness that the number of people with dementia will escalate into the future (ABS, 2006a; Access Economics, 2005). Participants in this research described how difficult it was to generate ACDs for the person with dementia when they were without decision-making capacity as illustrated in the following comment by Ms E:

*It took him (Dad) an awful long time to get Power of Attorney because she (step-mother) was actually being unable to comprehend which is difficult (Ms E).*

Ms E's acknowledgment of the difficulty in obtaining powers as substitute decision-maker is common when trying to act for people who are suffering from an illness which impairs their capacity for decision-making. Only if a person is in the early stages of dementia with a fair amount of lucidity regarding consequences of decisions they wish to make in an ACD will others be able to be nominated as SDMs (Cartwright, 2011). If the person's capacity to understand the consequence of their decisions is questionable, then a court appointed or tribunal appointment will be made which is what Ms E's father had to contend with. Knowledge and observation of the consequences that dementia had for personal autonomy was often expressed by participants through what they had observed in both family and professional relationships. This experiential knowledge of dementia was regularly identified by participants as



influencing their contemplation of ACDs for themselves and those under their care.

The fear that dementia holds for Boomers was demonstrated in a recent survey in the USA that found 23% of Boomers feared getting Alzheimer's disease as a result of prevalence of dementia in their families (44% of those surveyed had at least one family member with dementia) (Metlife Foundation, 2011).

However, dementia was not the only illness in which personal autonomy was seen to be compromised. Other illnesses participants in this research identified as requiring early ACDs were diabetes, cancer and cardio-vascular conditions. Some participants in this research had intimate knowledge and experience of many of these diseases in their families as evidenced in the following comment by Ms C:

*My father and grandfather were both diabetic...his (ex-partner) father died of asbestosis after being in the Navy, the mother died of lymphoma...they had horrible deaths (Ms C).*

The association of dying badly from these illnesses became a motivating factor for Ms C to complete her own ACDs, yet the literature described that many people with these diseases actually completed ACDs very late in the disease trajectory unless they were assisted and encouraged to do so earlier by HCPs (Reuben, 2009; Kramer & Auer, 2005; Harold, 2002; Rood, 1996). An example of the lack of timely ACD completion for those with a life-threatening illness was demonstrated in Temel et al.'s, (2009) research which found that among 2,000+ patients with different forms of metastatic cancer in a US hospital, only 20% had a documented DNR status. Metastatic cancer is a terminal illness so for 80% of patients being subject to CPR by default because they had not completed a ACD to indicate otherwise suggested that there was a lack of conversation occurring about QOL, ACP and death in this population.

Having experience of family members with debilitating illness and/or protracted and difficult deaths reinforced for participants in this research their existing knowledge of what life could be like if ACDs were not completed. Included in this contemplation was the possible need for future

accommodation in a residential aged care facility. As an example of how seriously Boomers contemplated future care scenarios, the Metlife Foundation (2011) study found 33% of USA Boomers had already considered care options should they get Alzheimer's and 44% had designated who should take care of them. Dementia was the illness most nominated by participants in this research as necessitating future accommodation in a residential aged care facility (RACF). Consideration that they may one day need to be moved into a RACF brought forth participant expressions of loss of dignity, neglect and continence issues which participants were adamant they did not want to happen to them.

### ***Avoiding Residential Aged Care Facilities***

Most participants in this research expressed their reticence to be moved into residential aged care facilities based on their knowledge and awareness of the consequences of care provided in many of these environments as demonstrated by the following comments:

*(I've heard) bad things about a nursing home...that he was lying around not being able to get anyone to attend to him...that he was in a wet bed.....they're (RACFs) both understaffed and under resourced and low status... they just used to take people's pensions...literally just serve them up the food from yesterday...it really was for the public patients who had nowhere to go (Ms B)*

*It's been my work now at Y (acute care hospital) and involvement in aged care.....my experience with advance care directives particularly with the nursing home, that sort of highlights it even more for me, not so much the urgency, but the necessity to get it (ACDs) done (Ms D).*

Knowledge and experience of RACF, whether anecdotal or direct, caused participants in this research to anticipate what might happen to them if their personal autonomy was not protected by an ACD. This knowledge was a catalyst for further contemplation of creation of ACDs. McCallum, et al. (2005) and others showed that images of care in the nursing home environment were often associated with people's decisions

to remain at home in the community as long as possible (AIHW, 2010c; Luppá, et al. 2009; Volandes, et al. 2009; Degenholtz, et al. 2004). However, participant belief in the ability of ACDs to prevent future living in or determine the care received in RACF were unjustified as the literature demonstrated conflicting evidence of the effectiveness of ACDs for protecting autonomy in RACFs. For example, Teno, et al. (2007) found that for residents of RACFs many care needs went unmet whether ACDs had been created or not. On the other hand, Silveira, et al.'s (2010) and Degenholtz, et al.'s (2004) research concluded that those who completed ACDs in residential aged care received the care requested as well as having a better chance of dying at home rather than in hospital or RACF.

Quality of life was again the factor of major concern for participant contemplation when discussing RACFs. Observations of QOL not only in RACFs but also through illnesses that made a person dependent on others generated much discussion about the elements that constituted QOL under these circumstances, as evidenced in the examples below:

*The quality is the most important thing in anybody's life, not the quantity...if they're bed-bound, if they're unable to take part in any social activity, if they live on their own, nobody visits them...an understanding of what they've had in their life, what they think they are now and what their further prospects are...I think people are living longer but not living better lives in a lot of cases (Ms C).*

*I suppose it's just the quality of life, the quality of death...no one wants to suffer but once you need quite a lot of assistance...you've got to cross your fingers and hope (Ms B).*

Ms B's equating of QOL with quality of death (QOD) meant that knowledge of QOL in these illnesses also made participants consider when life should end. Participants considered EOL by comparing dying in the past to dying in the present. This comparative contemplation was described through their experiences of loved ones who had died:

*My father expired fairly quickly with a very short period of ill health beforehand (Mr X)*

*My grandfather became ill overnight and died shortly thereafter, within a week or two (Ms E)*

All participants indicated that the past experience of another person's death, being a short illness followed by quick death, was preferable to the participant and informed their contemplation on how they would like their lives to end as illustrated in the following example by Mr Z:

*If I reach a vegetative state, I've got no, no inclination to be kept alive...I approach things from a quality of life perspective (Mr Z).*

Their awareness of the vegetative state and how this state compromised QOL was derived from their knowledge and experience of medical treatments which delayed death. In describing this awareness, such in-depth knowledge of the interplay between prolonged living, delayed death, QOL and medical interventions enabled participants to express the medical interventions they would not accept for themselves. Their choices are described in the following section.

### **Saying 'No More'**

For many people, having control over the events that occur in life is important, especially as people age and the risks in living become more acute (Kahana, 2004). Advance care directives provide this control and are actioned as a manifestation of this knowledge. All participants in this research, such as Ms C, described the control they would exert over their care if they were ever in circumstances where their QOL was compromised:

*I've been involved in both (my in-laws) deaths...If I can't be returned to the state that I was in prior, considering while I'm still in good health...I want no resuscitation...I'm to be left for at least 24 hours without any IV therapy...never under any circumstances am I to have a PEG feed...A peaceful, beautiful death is what everybody has the right to, not some violent chest thumping intervention (Ms C)*

Participants with experience of percutaneous endoscopic gastrostomy (PEG) described this medical treatment as particularly

undesirable. Studies by Lopez, et al. (2010) and Kuo, et al. (2009) revealed that the incidence rates associated with application of PEG feeding to moribund residents in aged care were related to families being persuaded to adopt these interventions for their family members by HCPs. Reasons for HCPs pursuing PEG feeds in residents included religious and professional biases against death and financial incentives in keeping residents alive.

Observation of the QOL associated with PEG feeding meant that although participants in this research were quick to say what they would not want to happen to them in unfavourable circumstances, they were not as facile in describing what should happen next when the medical treatment was stopped. Instead, participants described instead how they experienced others receiving palliative care and if the option was available for those in their care needing it, they made sure those people got it. This indicated participant acceptance of palliative care as an option in EOL care but participants did not state directly that this was an option they would choose for themselves in an ACD. This was one of several times throughout the interviews where knowledge was unable to assist with future decision-making and indicated some other factor was acting as a barrier for further contemplation of ACDs.

The literature described that families could be ill-prepared for long dying trajectories in those they loved (Bondoc, 2003). Participants in this research familiar with prolonged dying through experiences in their combined professional and personal lives understood the difficulties for families with delayed death. More importantly, several of those participants also understood what a delayed death might mean for the dying person. Familiarity with the lengthy process of dying revealed that these participants had knowledge of people who had considered assisted methods of dying:

*She'd become a member of Voluntary  
Euthanasia...could I get her enough pills to, so  
she could, you know, end it (Ms B)*

*He had made a decision that he was not taking  
medications any more (Ms C).*

Those participants exposed to requests for voluntary euthanasia understood that VE in South Australia was illegal but this did not stop them from discussing that it was an option for others at the end of life. It was less clear how participants in this research contemplated VE in relation to themselves. Rather, their mentioning of these discussions seemed to test the water and indicate their awareness of future scenarios in which one day participants might have to make these decisions for either themselves or a loved one. Discussion of VE was often accompanied by a sense of despair for those who suffered the consequences of prolonged life when they preferred to die. Seale (2009; 2006) and others have studied how VE requests affected HCPs and found that many HCPs were uncomfortable with these discussions but tried to respect the patient's request when legally able to do so unless they were influenced by religious or professional bias (Chambaere, 2010; Denier, et al. 2010).

As described previously, some participants' contemplation of EOL care was equated with quality of death (QOD) and quality of life (QOL). Research in the area of values for EOL care found that development of decisions for prospective healthcare treatment were influenced by socioeconomic factors such as; widowhood; moving into residential aged care; terminal illness; better education; or higher socioeconomic backgrounds. As a result, those from these backgrounds were less inclined to accept aggressive life-sustaining treatment (TCTEPC, 2010; Altmire & Naksook, 2007; Wilkinson, et al. 2007; HHR, 2004; Miles, et al. 1996). The socioeconomic factors of being better educated, employed and less inclined to accept life-sustaining treatments characterised all but one of the participants in this study. The difference between this participant, Ms F, and the others resided in her inclination to accept life-sustaining treatments regardless of the resulting QOL as indicated by cultural and religious preferences of her family regarding care and life-support measures.

*We have both discussed it and I'm not for that  
(taken off life support) and he is (husband)...he's  
also an organ donor and I'm not (Ms F)*

Participants, such as Ms F, indicated that culture and religion could have an influence on ACD decision-making even if they weren't prepared to identify these influences specifically. Nevertheless, participants were only too aware of the influence of culture for ACD decision-making and their knowledge is described in the section that follows.

### ***Cultural Influences on ACD Decision-making***

Though none of the participants identified a cultural heritage other than Australian, ancestral cultural influences were evident in several participants' ACD decision-making. For example, Ms F acknowledged that it was her family's expectation and hers that she would take care of her family members at home until the point of death. Luppá et al. (2009) suggested that families may not envisage placing their loved ones into institutional care but that life circumstances could change this decision as a person's functional and cognitive abilities decreased and the caring role became more burdensome. Ms F would not entertain any other scenario for her parents that did not incorporate her position as their primary carer. The literature indicated that people who did not contemplate alternative scenarios created challenges in promotion of ACDs in the community (Thrane, 2010; Temel, et al. 2009; Kramer & Auer, 2005; Harold 2002; Koenig, 2002; Turner, 1996). These challenges included negotiating the influence of culture, religion, race, and historical suspicion of the healthcare system. Temel et al.'s (2009) US research showed that those who were Caucasian and religious had increased documentation of medical treatment code status (such as for or against CPR); whilst younger, non-religious and black patients were less likely to have code status documented because of bias associated with age, race and historical mistrust of the healthcare system as well as religious and professional bias of medical practitioners (Temel, et al. 2009; Shalowitz, et al. 2007).

Seale's (2009; 2006) UK research showed personal autonomy in healthcare decision-making was being directly impacted by the personal religious beliefs of physicians. In the UK, in contrast to what the majority of the public wanted, many physicians were opposed to legalisation of

euthanasia because their religious and professional beliefs did not support the concept of personal autonomy in life and death decision-making (Grogan, et al.2009; LaRoche, et al. 2009; Lee, et al. 2009; Seale, 2009, 2006).

Religion did not appear to influence participants in this research, although two participants actually self-declared their non-religiosity as follows:

*I am an atheist... I have a view that everybody has a perfect right to believe in anything that they choose (Ms C)*

*I'm basically an Australian-born atheist, however...I would like to think that I would be able to act as she (partner) would want with a degree of cultural sensitivity and acceptance and awareness of religious beliefs and preferences (Mr X)*

Though they may not have been influenced by religion, participants acknowledged that the cultural or religious belief systems of others may make acting as an SDM unpalatable and jeopardise enactment of ACDs. This was a particular factor for one participant, Mr X, in his contemplation of ACDs

*cultural and religious issues may prove more of a hurdle to her (partner) acting as I would want (Mr X).*

Mr X's acknowledgement of his partner's inability to contemplate ACDs was identified as a barrier for his taking any action other than contemplation. Nevertheless, participants in this research identified that when discussions about cultural and religious elements of healthcare arose, this discussion often led people to discuss their funeral plans and what they would include for their funerals in ACDs.

### ***Funeral Planning***

All participants found that funeral planning was a form of ACP discussion that the public and their own family members seemed comfortable with and indicated that the topic of funeral planning was an



easy way to begin ACD discussions. One participant, Ms C, described how patients often felt able to tell her, as a nurse, the most intimate details of their funeral arrangements. Discussion of funerals frequently included reflection by participants of the differences between funerary practices today compared to those in the past. Ms E expressed her belief that society was losing the ability to support, acknowledge and provide closure on a deceased person's place in the lives of others:

*You know, I can remember my grandparents talking over the dinner table in front of the grandchildren... 'ah, you know Joe Blow up the road's dying' and it was part of life... (now) it's not general conversation... When I first started nursing 25 years ago it was OK, if you knew them and they were part of your community, everybody went to the funeral... I went to funerals to support my colleagues... if somebody local died, the whole town shut down for the funeral... if you wanted to find anybody, they would be at the funeral or at the cemetery where now that doesn't happen, these days... it's changed... because society has... we're not as supportive of each other... that support, unspoken support within the community is no longer there... it's only that direct link rather than supporting the supporter... (Ms E).*

Changes in societal practices of death and dying were felt more keenly by those participants with rural experience. Migration of the young to metropolitan centres meant different societal values were introduced to the rural community upon their return. Rural participants described that a difference they noticed between rural and metropolitan people contemplating ACDs was that people in rural areas often took more responsibility for getting their affairs in order and discussed why this might be so:

*Rural areas don't have the same accessibility to home services that you do in the city ... A number of the clients we had from X (small country town) were from wealthy farms... these were clients that came in with their ACDs already done ... they seemed to respect whatever their family members wanted and in many cases it was obvious that the ACDs had been discussed at length before they came into the nursing home (Ms D).*

Those participants with rural experience learned from and contemplated the attitude of their rural acquaintances who knew that because healthcare and welfare services were much less accessible in rural areas; decisions about healthcare and welfare had to be thought out well in advance. Participants named this process of ACP in the rural environment as *estate planning*. The estate-planning process included not only funeral planning but also Wills and ACDs. The ACDs most often named by participants in association with this process were EPAs and EPGs.

When asked about their understanding of the difference between these two instruments, participants often provided incorrect information. This lack of specific understanding about the instruments was acknowledged by all participants as the reason for their engagement with this research. Nevertheless, all participants did have knowledge about wills and this was the form all participants described as an ACD. The identification of wills as an ACD over the legitimate instruments and the implications this has for completion of ACDs is described in the section that follows.

### ***Talking About the Same Thing***

As indicated, when participants were asked which of the formal ACD instruments they had completed as part of their own estate planning, all participants nominated their Will as the instrument containing their advance care instructions. The nomination by participants of a Will being an ACD instead of the legitimate SA ACD instruments indicated incomplete and inaccurate knowledge of all of these instruments despite participants confessed previous experience of ACD implementation. Brown's (2006) research found that this was not uncommon and that even though Wills are not ACDs, they were often named as ACDs by both HCPs and the public alike.

The emphasis that all participants placed on Will creation as part of the ACD decision-making process led to confusion during the interviews of whether participants had actually completed formal ACDs. An example of this confusion is demonstrated by the following comments:

*(EPA) only covers what happens to my goods and chattel and money...I mean I just did what I assume was the standard enduring power of attorney...because it's in legal terminology, it's not like just writing a simple sort of thing...I thought that if you had Enduring Power of Attorney, (It) gave me some authority medically and it doesn't (but I now know) if you have Guardianship, you do (Ms B).*

*I thought they were given different titles...not these titles...I think advance care directives it's not the terminology that gets used in some situations – it sort of confuses me as to what it means...advance care directives sort of mean the all encompassing, I mean that was one that covered the lot...is that the one, the anticipatory direction, is that the part that says what you want done in the event of...Is it one total form or are the forms separate because what I recall seeing was two forms: one EPA and the other one was Medical, so that was on the other form, there was not an Anticipatory direction on that form (Ms D).*

*(After careful review of the transcripts, it was found that five of the participants had completed at least one form of ACD- author's note).*

It was described in Chapter Two that confusion with these instruments often arose because of the inconsistencies in development of these as well as the legislative Acts supporting them (TCTEPC, 2010; Lynch, et al. 2008; Parker, et al. 2007). This confusion of the public regarding these instruments generated a significant amount of opinion against the use of these instruments in the literature (Collins, et al. 2006; Fagerlin, et al. 2004; Lynn & Teno, 1993). The debate in academic and political circles about the necessity for and continued use of these instruments has confused HCPs about the legality of these instruments and the roles of SDMs and the decisions they can make (TCTEPC, 2010; Parker, et al. 2007; Holt & Vedig, 2006; Reisfield & Wilson, 2004). Participants in this study shared that confusion. This was illustrated in their lack of understanding of the instruments they had created for themselves as well as their description of the conflicts they witnessed when SDMs attempted to act for others without proper authority.

Participants' incomplete and inaccurate knowledge of these instruments indicated that information currently available on ACDs was neither clearly articulated nor generally well understood. Participants indicated that their lack of knowledge was very much the norm both in the healthcare environment and in the community as evidenced in the following exemplar:

*The general public I suspect is largely ignorant, uninformed, poorly informed and probably a lot like me, well, reluctant (to be informed) (Mr X).*

To ascertain whether this lack of knowledge was due to the ACD forms being complicated or difficult to complete, participants were asked about their ability to complete the forms. Most participants did not believe the forms were necessarily difficult but completing them was and in the following section particular areas of frustration for participants are described.

### ***Filling in the Forms***

Several participants felt the lengthiness of the forms as well as the requirement for multiple certified copies was onerous. Additionally, one participant identified that those with poor literacy skills would find the forms challenging as she explained:

*I think they could probably be written ...less legal for the want of a better word and having had some experience with them in my position...I know that my Dad and to some degree Mum had issues with interpreting what they were saying (Ms E).*

Ms E's contemplation of how the forms could be enhanced included recognition that the older generations would have difficulty completing the forms and would need assistance to do so. Identification of generational differences in being able to understand the need for and ability to complete these documents indicated that Boomer participants in this research had more familiarity with both the instruments and their necessity than older generations. Familiarity can be a platform for translating knowledge into practice. The familiarity of knowledge demonstrated by Ms

E's indicates that future uptake rates of ACDs may be dependent upon generational knowledge and familiarity of these instruments.

Two participants in this research also identified that the reluctance of the public to engage in ACD decision-making was countered when certain situations arose in life that provoked a person to complete ACDs. These situations included putting affairs in order prior to local or overseas travel but especially if going overseas for the first time. The following examples demonstrated these participants's association of travel with the need for ACDs:

*My husband had never flown in a plane... We were going overseas on a holiday and needed to sort of make out our will in case something did happen so the boys would be taken care of (Ms F).*

*There may be an event where both people are in a car accident...if you happen to be visiting another state (or) holidaying somewhere else in Australian or another country, you've still got access to (ACDs)...people do move around a bit and go on holidays (Mr X).*

Participants contemplated that the reason people would actually complete ACDs at these times would be to prevent putting an SDM in a position of crisis without direction. As a result, more than one participant suggested that perhaps these instruments could be advertised in travel agencies. Not all participants accepted the need for such deliberate educational strategies however. One participant, Ms F, felt ACDs should be optional and that education or advertisement should not be forced on people, for example when travelling. The difference of opinion as to whether promotion of ACDs should become more prominent signified that education for different groups in society on the benefits of ACDs may need to differ. Evidence to this effect was recently described in studies by Detering, et al. (2010) and Silveira, et al. (2010) which showed that when ACDs were discussed with the public in a language and context they could understand by knowledgeable HCPS, then ACD construction was more often accepted and implemented.

Ms F's reluctance to be forced to engage with these instruments was also found in some of the other HCP participants even though HCP participants all agreed on the importance of these instruments for acute care crisis management. The reluctance demonstrated by participants to create these instruments often centred on their knowledge of how ACD discussions could adversely influence their relationships with others. Participants identified that successful use of ACDs was dependent on an effective relationship with an SDM who could withstand the pressures of ACD decision-making and uphold the autonomy of the person being represented. The importance of relationships to participants in this research and how it influenced their contemplation of ACDs is discussed in the next chapter, *Contemplating Relationships*.

### ***Summary***

This chapter described how participants in this research developed their knowledge of ACDs and how this knowledge influenced their use of ACDs using the BSPP of Contemplation. Contemplation of ACD completion occurred within and between stages of contemplation with the first stage of contemplation described in this chapter *Stage 1: Contemplating Knowledge*. Description of this stage of contemplation began with demographical information on the participants in this research and provided a context for the individual participant's contemplation of ACDs

Theoretical development of the first stage, *Contemplating Knowledge* was introduced through description of forms of knowledge informing participant contemplation of ACDs comprising awareness, experience, and knowledge of ACDs as derived through association with others. Awareness itself was described as a BSPP by others in the literature and these other awareness contexts were compared with the awareness demonstrated by participants in this research.

Comparisons of awareness contexts indicated that for participants in this research there were other elements of knowledge more or equally important when contemplating ACDs. Of particular importance was experiential knowledge. Experiential knowledge of ACDs developed

through witnessing how these instruments, or lack thereof, assisted or detracted from perceived QOL for those without decision-making capacity. Participants in this research gained experiential knowledge through multiple lenses; as healthcare professionals, family members and as members of the general public and named many factors that influenced this experiential knowledge.

These factors became categories or themes of theoretical development for the first stage of contemplation. Themes combined findings from participants with discussion of the literature to create in-depth understanding and were described in sub-headings illustrating their particular influencing contemplation of knowledge of ACDs. These themes included: *the ageing process; meeting the needs of others; experiencing the healthcare system; being the communicator; understanding illness; avoiding residential aged care facilities; saying 'no more'; cultural influences on ACD decision-making; funeral planning; talking about the same thing; and filling in the forms.*

Factors identified as unique to the experiential knowledge of these research participants were, in brief: their understanding of the consequences on future healthcare and welfare management of having dementia or other cognitive impairments; funeral planning as a means for ACD discussion; and recognition of the difference between the practices of dying today compared to dying in the past.

Participants always described their knowledge of ACDs through affiliations with others in their capacity as a healthcare professional and family member. In these capacities they were able to observe the effects of ACDs under different care scenarios. Having this more direct experiential knowledge consolidated general knowledge that participants had about these instruments and their functions. Nevertheless, participants showed a lack of understanding of the specific instruments and this lack of clarity created confusion as to whether participants had actually created ACDs for themselves. Regardless of whether they had or had not, participants expressed that ACDs were an important part of future healthcare management to prevent prolonged life at the expense of quality of life. Helping others to understand the importance of QOL was not easy

and depended on positive examples of communication and implementation of ACDs. In communicating with others about ACDs, participants described that it was necessary to know the values of those having ACD conversations if discussions for uptake of ACDs were to be fruitful. These values often became clear during discussion of funeral planning and funerary practices Will creation and completion of ACD forms. Completion of the actual forms was identified by participants as being difficult due to both language of the forms and other factors such as culture or age inhibiting completion of these instruments.

Finally, knowledge through awareness and experience of the use of ACDs generated familiarity with these instruments such that participants contemplated creation of these instruments for themselves. Without this familiarity, participants observed others would be ignorant of the purpose or need to complete these instruments. The influence of others for participant knowledge of ACDs was pivotal when participants contemplated ACDs for themselves. Acknowledgement of the importance of relationships to contemplation of ACDs is described in the next chapter, Chapter Five which discusses the second stage of contemplation: *Stage 2: Contemplating Relationships*.



## **Chapter 5 - Identification of the Factors Influencing ACD Decision-making by SA Boomers – Part B**

### **Stage 2 - Contemplating Relationships**

This chapter describes the second stage of the basic social psychological process (BSPP) of ACD decision-making by SA Boomers. The chapter follows the thematic approach developed in Chapter Four but the focus is on the second stage of contemplation that participants engaged with when considering ACDs. A complete list of themes for stages 1, 2 and 3 can be seen in Appendix 5.

The second stage of contemplation, *Contemplating Relationships*, was sequential to the first stage in many respects as participants described how their relationships were affected by their observations of other SDMs, their role as an SDM and their choice of SDM for themselves. Properties comprising this stage can be seen in Appendix 4 but encompass the elements of relationships, communication and time as the conduits for knowledge development of ACDs. In-depth discussion of the importance of these different elements for ACD decision-making by participants in this research is described under the themes that follow.

#### ***Having the Discussion***

In Chapter Four, participants identified factors such as ageing, illness and QOL as influencing their experiential knowledge for ACD decision-making. For one participant however (Mr X) these factors had less significance than the cultural and religious background of his partner. Her cultural background prevented any discussion altogether of ACDs. Not being able to discuss ACDs with his spouse stopped any further attempt at ACD completion by this participant.

Brown & Jarrad (2005b) argued that having the conversation with others was the single most important step of ACD decision-making. Kahana (2004) found that most of these conversations were held between a person and family members without any engagement of HCPs. When families had questions or were ready to contemplate their own need for

ACDs based on their health, this was the time when they often sought the advice of HCPs, particularly medical practitioners (Detering, et al. 2010; Deep, et al. 2008; Black, 2006). Though the attempt was made, often these discussions did not transpire for a variety of reasons.

The literature revealed that reasons for delay in ACD discussion included: confidence of the medical practitioner in discussing ACDs; HCPs not wishing to acknowledge death; medical practitioners not having time for the discussion; or cultural or religious bias of the medical practitioner or HCP (Janvier, 2010; Degenholtz, 2009; Altmore & Naksook, 2007; Hancock, et al. 2007; Noble, et al. 2007; Seale, 2006; Layson, et al. 1994). Larochelle, et al.'s (2009) study of physicians and surgeons found that organisational factors could also prohibit physicians and surgeons from conducting these conversations. Organisational factors identified included: lack of training in EOL conversation; medical practitioners not feeling their role is about dying; and financial disincentives for the time taken to have these conversations. In contrast, nurse participants in this study identified that the best conversations witnessed on ACD discussion were by medical practitioners in the palliative care environment. In this environment, communication on ACDs was conducted compassionately and thoughtfully such that personal autonomy was promoted and respected. Goldsmith, et al. (2010) found that collaboration between HCPs, as occurs in the palliative care environment, also promoted increased satisfaction with patient care. Perceived barriers to this collaboration centred on the willingness of physicians to participate with others (Goldsmith, et al. 2010).

For participants in this research, being able to have supportive conversations about the trajectory of dying for their patients or loved ones engendered relief and confidence in the decisions they made on behalf of others. To engender conversations supportive of others also required participants to have a clear understanding of the values of the person being represented.

### ***The Values of Others***

Participants described the importance of understanding the values of others primarily when they discussed their role as SDM for their parents.

One participant, Ms C, provided an example of the extent of knowledge that could be obtained when child-SDM ACD conversations were held:

*We didn't ever actually have a written advance care directive but I realised how necessary it was for me to know what both my parents wanted...they did not wish to be on a ventilator, they did not wish to have any heroic means...they wanted me to be able to voice that for them (especially when) in some of the nursing homes (like) the one my father had to go into for five months ... there was no need for him to have a pad of any description and (I'd) take it off and take him to the toilet even though it was becoming more difficult for him to walk with me ...I knew this was important (to do for him) because I knew my father (Ms C)*

Understanding the values of her parents enabled Ms C to advocate confidently for appropriate care for her father at the time required. These values weren't always so easy to ascertain for other participants however. Mr X provided an example of the frustration that could result when family members made unclear directives:

*(Mother) tells me and my sister that we should just sign here and act on her behalf...I just need to be clear on what (mother) means by 'when (she's) a vegetable, pull the plug...I mean there are probably grades in between... For me as a son to try, my sister didn't want to have the conversation, just 'Mum wants me to do this, fine'...but it doesn't give me enough to go on... I think with my mother, if she was able to have an initial conversation with someone to help clarify, discuss, refine things down and then for people that are going to be appointed to be involved in that discussion again, would be useful (Mr X)*

Participants contemplated that with a narrative from the caregiver, it was easier for the healthcare team as a whole to provide the care required for both the patient and caregivers. Understanding the utility of clarity in decision-making was confirmed by participants not only through their experience with family but also through their role as HCP. Both roles required advocating for others as demonstrated by Ms C.

### ***Advocating for Others***

Being a HCP enabled participants to contemplate the vulnerability that some people may have when being cared for in the healthcare system. Their awareness and experience of what could happen to the personal autonomy of vulnerable people was expressed as a particular concern and some participants adopted an advocacy role for such patients as demonstrated in the comments by Ms E:

*In particular, the one patient, I was quite adamant about it, you knew her family was not going to cope... The privilege for me...when I've had to stand up and fight for this person as an advocate was the fact that they have been long-term patients coming in and out of acute and palliative care so the directives were in place early in their illness and as their illness progressed, the family were having issues and the patient themselves would continually enlist the nursing staff and say 'make sure I get what I want' (Ms E).*

Evidence of the advocacy role played for others in ACD decision-making was provided multiple times throughout the interviews, particularly by the HCPs, four of whom were nurses. Ms E felt that having clear and consistent instruction in the form of ACDs legitimised her fervour in advocating for her patient against others' wishes. This experience proved to Ms E that knowledge of ACDs could provide the impetus necessary to act for others with confidence when the advocate was not the designated SDM.

Propp, et al. (2010) found that nurse communication to other healthcare team members and the way in which they did it could enhance the ability of the healthcare team to provide desired patient care. This was because nurses were prepared to stand up for each other as well as patients and families (Propp, 2010). Nurses often tread a fine line when advocating for others however as described in the following theme.

### ***Finding a SDM***

Participants discussed how advocating for others sometimes actually required them to become the SDM for those who lacked a nominee. Healthcare professionals in South Australia are not permitted to act as

medical agents for patients under their care but some did so temporarily when processes for guardianship were not in place. Participants contemplated that this happened more frequently in RACFs than in the acute care environment as people grew older and friends and family died.

Taking on the role of SDM under these circumstances though sometimes left the resident/patient and HCP in a vulnerable position psychologically, physically and professionally. Acting as an SDM without legitimate authority placed the HCP in conflict with legal, ethical and professional conducts of care (Australian Nursing & Midwifery Council/ Royal College of Nursing Australia/Australian Nursing Federation, 2008; South Australian Government, 1995). Participants in this research who had been placed in these situations described relief when formal appointment of an SDM was made in an ACD as described in the following exemplar:

*Yeah, it did (provide a sense of relief getting POA) because it was a legal document that he was giving me permission to do what I had been doing and was going to do (Ms D)*

Formalisation of the SDM process clarified and acknowledged the responsibility and duties of the SDM as well as their relationship with the person being represented. When an SDM could not be found for a person, participants acknowledged the assistance of the Public Trustee and Guardianship Board in these situations. Many participants gained familiarity with these organisations through their participation as HCPs for families requiring an independent decision-maker as illustrated by Ms C:

*The Guardianship Board worked out quite well because they showed them (relatives) that they actually have no control any longer because of their behaviour (Ms C)*

In general, participants described successful dealings with these institutions on behalf of patients or clients but understood these institutions were not to be treated lightly and should be seen as a last

resort for protecting individual autonomy as illustrated by Mr X's comments below:

*I've lodged applications for clients...from personal experience, no unnecessary delays, no extended delays, but I've certainly heard reports that it can take some time to have orders put in place...and their forms are horrendous...Very legalistic, quite daunting, it's benches and people and a very structured process and fairly serious looking people...it's a fairly serious thing to front the Guardianship Board and the powers that they have...they are the independent umpire, I guess (Mr X).*

When it came to participants having to deal with these institutions on behalf of family members, the experience was not described quite so positively. Participant dissatisfaction in dealing with the Public Trustee and Guardianship Board centred on these institutions seeming to have no understanding or desire to create decisions suitable to the values of the person being represented. Examples of what participants meant by this are presented below :

*I wouldn't want them making decisions for me...they don't know me, they don't know my history...the Guardianship Board might take the course of expediency or whatever...we've had trouble with the Guardianship Board (Ms D).*

*It was quite intimidating for him (Dad)...he made a comment...they think I'm going to abuse her?' He did feel a bit intimidated by it all (Ms E).*

Often institutions like the Public Advocate or Guardianship Board are approached when people, either HCPs or LPs, perceive poor care or neglect of an individual (OPASA, 2003). Griffiths, et al. (1997) identified that when guardianship orders were placed, the outcomes were uncertain and could actually restrict personal autonomy rather than enhance it. This could then engender negative perceptions by the lay public of both institutions and healthcare professions. Awareness of the need for an independent 'umpire' generated contemplation in participants about their advocacy role for their own parents. When the HCP was the family SDM having ACDs seemed to provide extra reassurance that they had

legitimate authority to act for their parents as demonstrated in the following comments by Ms E and Mr Z:

*The bonus for me is they (parent's directives) are very clear and I'm very clear about them (Ms E).*

*Mum could see the advantage that you've got quite clear, you've got legal authority (Mr Z).*

Participant experience of ACD decision-making for others produced deeper contemplation of who might act for them. In contemplating the appropriate choice for themselves of SDM, they were influenced by their knowledge of the difficulties being experienced within the acute and aged care environments. This engendered contemplation of the characteristics required of those nominated as SDM as described in the section that follows.

### ***Who Will Decide for Me?***

Participants found that the SDM needed to be strong enough to withstand the influences of others and support the previously made decisions of the individual they represented. In contemplating on these characteristics, participants acknowledged that though they felt the parent-child relationship was an important consideration when choosing an SDM, they also knew that not every child was capable of being an SDM. This knowledge came from their experience of witnessing the dynamics of SDM decision-making for others as both HCP and SDM. Healthcare professional participants involved in ACD discussions with clients were able to use their experience to emphasise to clients and client families the careful consideration required in the choice of SDM:

*(When discussing advance care directives for the disabled) often when parents were getting older... (I'd) express concerns about what was going to happen with their son or daughter... if siblings no longer want the responsibility for a variety of reasons...then for the client's financial and legal situation...the organisation became the guardian (Mr Z)*

*(I recommend) that they (clients) think very carefully about who they would like to represent*

*them if that worst case scenario did happen... Often, it's the stronger member of the family group that has been or think they have been allocated the power...it's the one with the attitude and the mouth that seems to acquire the powers, perhaps because they are more outspoken (Mr X)*

The experience of Mr Z and Mr X clarified the ramifications of making an unwise choice of SDM. Contemplation of SDM characteristics by participants identified who they would *not* choose as SDMs for their parents or themselves. Their choices were frequently expressed in relation to the family composition of their individual circumstances as described in their genograms illustrated in Appendix 11. The genograms demonstrated that the family composition of these Boomers was not as straightforward or similar to families of past generations, including their own. Participants often indicated that because of the more complicated structure of their family life, conflict was inevitable when discussing major issues such as ACDs.

### ***Managing Conflict***

For participants such as Ms D and Ms E, they had experience of the conflict that could occur in families when an inappropriate person or others outside the immediate family had been chosen to act on behalf of parents:

*When my father died and then two months later my step-mother had a brain tumour diagnosed and she didn't have any advance, she didn't have anything and her son was in NSW and I was more a daughter to her than what her son was to her so we had trouble with the Guardianship Board ...I'm one of 7 and we're all estranged from (mother) and you know so I worry about her (Ms D).*

*The boys in the family who were the dominant ballplayers were quite adamant that they wanted him to live regardless of what happened and regardless of the outcomes...as a result of all of this, she's (Mum) not spoken to her brothers since...for a long time Mum was quite ostracised for what she felt Grandpa wanted (Ms E).*



As illustrated by Ms D and Ms E, participants reflected that when ACDs or the choice of SDM had not been discussed in advance with family and friends, it was a recipe for conflict and negative consequences that had a lasting effect on all involved in the decision-making. To prevent such conflict from arising, all participants discussed the necessity of the SDM being supported by healthcare personnel, family and others in the decisions being made.

### ***Supporting the SDM***

For Ms E and Ms F, being supported meant having the psychological support of their husbands to assist them in their SDM role for parents as described below:

*It's going to be very hard but I've got (husband's) support (to enact her parents ACDs) which is good...he's sometimes more level-headed than I when it comes to decisions with Mum and Dad  
(Ms F)*

*If I was doing this on my own...I'd probably be a bit shakier...to be honest to stand up to 4 other siblings...it's quite intimidating...I have a very supportive husband...so I'm very lucky in the fact that as their (her parents) advocate, I'm supported  
(Ms E)*

These participants contemplated that they couldn't or wouldn't be able to perform their SDM role without this support. The literature is sparse on the actual support being given to SDMs other than HCPs assisting SDMs in the decisions they are making as demonstrated in the research by Wendler and Rid (2011), Salmond, (2011) and others (Ruff, et al. 2011; Volandes, et al. 2009). Their research showed the burden of SDM decision-making is increased when there is confusion or conflict and that communication is the key to preventing the moral and psychological distress arising from such scenarios. This communication needs to include other family members who may feel they have a right to participate in decision-making. In Australia, these scenarios are not uncommon as evidenced by research conducted by the Conflict Resolution in End of Life Settings group in NSW (2010). Their report provides strategies for HCPs

to reduce the psychological and moral distress for all concerned in end of life care including more preemptive attempts at communicating the particulars of the situation facing families of loved ones in these circumstances (NSWDH, 2010).

Participant identification of the need for support from both family members and the healthcare system led them to consider who in their family would be the best SDM for them. In contemplating on this, participants often described the tensions that existed in their families. For example, three of the participants in this research identified that they were a member of a step-family, two participants were adopted, and two participants were from self-described 'dysfunctional' families where other siblings or their partners could not be relied upon. The consideration of other siblings providing care for parents was identified by participants as something that parents might expect but participants indicated that based on their HCP and SDM experiences, this expectation could be a false and contentious one within families.

### ***Seeking Sibling Support***

Participants commented that their siblings were loath to take up the role of SDM or were otherwise inappropriate to share the responsibility of this decision-making. Two participants, Ms C and Ms E illustrated why their siblings were not being considered as an SDM for them:

*My sister is totally out of the loop as far as caring for Mum...she's younger than me...we've always protected her from I guess reality in a lot of ways...my sister doesn't live in the real world (Ms C).*

*There's five children in our family, I've got two in New Zealand and because we had a fairly dysfunctional type family...the decision is with me...the other guys (siblings) a) don't want to talk about it, b) don't want to know about it, and c) don't want to interact with Dad or Mum anyway (Ms E)*

Participants indicated that not being able to depend on siblings to assist with care for parents doubled the load for the participant. A recent

study by Salmond (2011) indicated that the phenomena of being both a HCP and a family SDM can be difficult for those involved in this scenario because the HCP may seek to dismiss the individual's ACDs when their professional knowledge of treatments and outcomes were able to provide more expert assessment. Additional areas of concern for HCPs acting as SDMs was that family members expected the HCP to do all that was capable of being done regardless of QOL or care for the person being represented. In Salmond's (2011) study, HCPs who were family SDMs chose more invasive and intensive treatment for their family member, even though they knew the procedures would be futile or yield a poor QOL.

Research by Khodyakov and Carr (2009) found that when siblings were involved in ACD decision-making for parents, ACDs could be helpful during the parent's death, but could also exacerbate distance in susceptible sibling relationships post-parental death. Though it would seem more logical to choose siblings who have a shared history with the person creating ACDs, participants identified that siblings might not be chosen because: a person had no siblings; siblings would not want to be involved; siblings had no ability to act as SDM (through physical or psychological barriers); siblings were not available due to location; or family dysfunction prevented them from acting as an SDM.

Having already been tested as SDM for family members, several of the HCP participants in this study indicated that this had engendered greater confidence for them of being able to withstand non-SDM family member pressures and concerns. Other HCP participants, who had not yet been tested, acknowledged that it would be difficult for them to act as strongly as they currently felt they could, but with the support of others, they were determined to do their best.

For LP participants, being able to act confidently in the role of SDM was less convincing, though the intent was voiced to do the best they could. Without intimate experience of medical treatments and outcomes, LP participants said that it was possible other factors would influence the decisions they made and lead to overriding ACDs of parents or spouses as illustrated by Ms F:

*"I believe that it would go against his wishes if I didn't (follow instructions) even though I don't agree with it...(however) I still think that if you're on a life support and you have that little hope, there might just be that miracle somewhere along the line that he might recover... (I said) you don't have to think that I'm just going to turn the machine off and go (Ms F)*

Research by Melhado and Fowler Byers (2011) and Shalowitz, et al. (2007) concluded that many SDMs were inaccurate in their decision-making for others because patients may not really want to share decision-making with particular family members or physicians (Melhado & Fowler Byers, 2011). Reasons for not wanting to share decision-making with family members included the patient's perceptions of religious or ethical conflict on the part of the SDM. This perception was verified in research literature indicating that reticence by SDMs to enact ACDs may be a result of SDMs believing ACDs are a back door method to cessation of treatment through actively encouraging the death of patients who are debilitated and dying (Grogan, et al. 2009; Ward, 2009). Participants in this research indicated that this was sometimes the case in their experience and was a reason for the confusion that occurred between parties trying to encourage ACD decision-making on behalf of others. Ethical and religious conflict leading to misperception of the intent of ACDs combined with limited experience of the consequences of medical treatment decision-making meant for participants in this research that contemplation of the choice of their own SDM required very careful consideration.

Knowledge and awareness that certain family members would be inappropriate SDMs, participants evaluated others, (e.g. children or friends) in their social network who would be more appropriate and willing to act as SDM. For participants in this research, the other SDMs considered were children, where available, over siblings. Data analysis in this research of the SDMs chosen by participants for themselves revealed that none had chosen a sibling but that those with children had chosen one or several of their children to act as their SDM. Discussion of the

reasons for choosing children as SDMs is described in the section that follows.

### ***Considering Children***

Participants with children identified that discord in their sibling relationships influenced them to nominate their children to act as SDM for them instead of their sibling. Participants described that they chose this course of action only after establishing additional support mechanisms for their children to act as SDMs and uphold the participant's autonomous decision-making as illustrated in this comment by Ms D.

*I've told my daughters what I would like to happen but you never know at crisis time whether there's conflict between the two of them and one does, one doesn't, who wins, I don't want any sort of friction...I'd ask one of my brothers or sisters if my kids weren't going to do it. I'd rather have someone who meant something to me and would be willing to do what they felt that I would like (Ms D).*

Ms D further indicated that she had asked particular siblings to assist her chosen daughter to carry out the instructions of the participant at the time required. Participants described that it was important to provide additional familial support for children who were still relatively young. The age of children nominated as SDMs for participants in this research ranged from 20-35 years of age. These ages are much younger than what has been described in the literature for surrogate age ranges, as evidenced in a recent literature review on support systems for SDMs by Melhado and Fowler Byers (2011). The mean age range of SDMs in their study was 48-63 years of age. Younger SDMs for participants in this research may reflect the fact that participants were older when they had children, reflective of the Boomer generation's use of the contraceptive pill to manage family size and timing (Kaplan, 2009).

The familial composition of participants also influenced their choice of whether spouses or children should be their SDM: two participants were divorced, so chose their children, whilst one participant who was married felt his daughter was the more suitable candidate. Those participants

without children chose other family members. For example, one participant chose their elderly parent as their SDM as no children or siblings were available to act on her behalf. This participant, Ms B, described her situation as follows:

*My sister doesn't live here...my brother doesn't live here... (So I've nominated) my mother, who's 87 (Ms B)*

In the case of Ms B, naming elderly parents as SDMs is not an ideal situation as recommendations on ACD creation suggest naming an SDM who is younger, rather than older (OPASA, 2003). However, Ms B's decision-making indicates just how difficult it can be to find someone to act as SDM if siblings or children are unavailable, unwilling or inappropriate nominees.

For those participants with spouses and underage children, they chose their spouse as their SDM. More recently, Nolan, et al. (2009) and Wendler and Rid's (2011) researched whether loved ones really wanted to be a part of the decision-making required of them. Nolan, et al.'s (2009) study found that spouses were less likely or willing to make decisions than non-spouses. Participants (Mr X, Ms F) confirmed the truthfulness of this observation when describing how partners might be unwilling or unable to act as SDM or carry out ACDs. Nolan, et al.'s (2005; 2009) research found that it was experience in decision-making as a carer that increased the SDM's ability to act. Acting as a carer provided experiential knowledge of healthcare and welfare decision-making which reflected acceptance of mortality and shared understanding of suffering. Participants in this research realised that acting as the SDM was quite stressful because it required both the SDM and the person being represented to consider mortality and what it means to suffer; or prolonging life at the expense of QOL. Kellehear (2009, p. 388) called death and suffering the "twin existential titans" of existence. He argued that insights into both of these fields as they related to each other were important in understanding how the concept of death has become more complicated in today's technological world.

When participants were guided to contemplate further on the content of their ACDs, usually under the direction of a solicitor, they realised that nomination of the spouse as SDM was insufficient to protect the interests of their children. This then led several participants, Ms E and Ms F, to consider others they trusted to act on behalf of themselves and their children as demonstrated in the comments below:

*When we made our Wills...if anything happened to my husband and myself...they (godparents) would be the ones in charge of my children and property...I wanted the boys to continue their education...to make sure that whatever assets we had, that would be theirs and that they would be taken care of (Ms F)*

*In our wills we've made the stipulation that our children don't have to make any medical decisions until they are 21 about our care. Our solicitors will make those decisions...because I wanted to protect them (Ms E)*

Needing to consider both sides of the situation, (e.g. SDM for themselves and their children) highlighted the complexity of SDM decision-making for these participants. In considering these guardian arrangements, participants such as Ms E identified that emotionally it was “scary” considering establishment of such formal arrangements. The emotional impact of nominating an SDM was raised by all participants as an inhibiting factor in contemplation of ACDs. This was countered however by participants’ faith and trust in those chosen to act for them whether formally or informally.

### ***Faith, Hope and Trust***

Some participants, such as Ms E, described the decision-making process in terms of fear; whilst others expressed faith, hope and trust that their autonomy would be respected through either people or systems supporting ACDs as illustrated in the following comments by Ms C and Ms E:

*(Family members) trust me implicitly to do the right thing for Mum ...I know exactly what my son*

*wants...I will do what he has told me he wants (Ms C)*

*It has been a verbal contract for many years basically...they've got ...same values, it was always a contract between us...it's just nobody outside the loop knew about it (Ms E)*

Faith and trust were expressed by participants in their ability to act as an SDM and enact the ACDs of the person they represented as well as their confidence in others to do what was agreed. Notwithstanding the faith and trust they placed with others, participants often couched their expressions of trust and faith with hope that their relationship with and as SDM would be strong enough to enable ACDs to be implemented. Ms E expressed this most succinctly in the following exemplar:

*You know when you come to make those sorts of decisions in your life, it's easy to sit in a lounge room making these notes and then taking them to the solicitors and putting them on paper and yep, that's what I want, but when you actually have to go 'no, let her go', I hope so (they'll be able to carry out the ACDs) (Ms E)*

When this faith and trust in others and with themselves proved successful, participants experienced the rewards of witnessing a “good death” in both their personal and professional lives. The paradox of faith, hope and trust in SDMs to do what would be required of them seemed to underpin much of the contemplation of participants in this research of whether or not to action ACD creation or choose an SDM.

Hope can mean different things to people in both expression and process and the expression of hope by HCP and LP participants in this research when contemplating ACDs suggested a difference in the intent of this term. As previously illustrated, those participants with HCP experience expressed hope that others would enact the ACDs as requested; whilst, the LP, Ms F (see quote under *seeking sibling support*), expressed her hope in a religious or virtuous sense as evidenced by her use of the word ‘miracle’. Concepts of virtuous hope in the literature with regard to ACDs have centred on fostering an ill person’s ability to continue living successfully whilst experiencing



debilitating disease (Davison & Simpson, 2006; Back, et al. 2003).

Ms F's perspective illustrated what the literature has described as LP SDMs having little understanding of the successfulness and consequences of life prolonging technology (Clark, 2002; Back, et al. 2003). Clark (2002) suggested that though the rise of palliative care sought to provide a gentler and guided understanding of what was required of SDMs to support a dying person, including provision of hope that a pain free and peaceful death would occur; these efforts were undermined by medicalisation generating perspectives such as those expressed by Ms F.

Clark (2002) described the effects of medicalisation on hope through the work of Ivan Illich (1975 cited in Clark, 2002) who predicted that medicalisation would change the public perspective of death and dying. This would occur through: an unwillingness to accept death and suffering; creating a state of war against death through media and professional conduct; crippling the rituals of personal and family care as well as death and dying; and making into social deviants those who accept the natural course of death. Research by Salmond (2011) and Wendler and Rid (2011) found that it was very difficult for SDMs, whether knowledgeable about healthcare technology or not, to relinquish emotions like hope for dying loved ones. They suggested that assisting people to relinquish hope for that which cannot or should not be changed would increase the likelihood of the desired outcome for the individual creating an ACD (Salmond, 2011; Wendler & Rid, 2011). Back, et al. (2003) described that physicians should use a dual approach to hope in their patients that "hopes for the best, but prepares them for the worst" to mitigate the emotional disappointment of medical treatments that don't produce miracles.

As evidence of the dualistic nature of hope, Ortony, et al. (1988) suggested that hope expressed pleasure at the prospect of a desirable event, but was dependent on the likelihood of the outcome desired. This ideation of hope is consistent with the hope expressed by both HCPs and LPs in this research.

Charland (2008) proposed that emotions such as hope and the values they expressed were reasons for initiating an action. For participants in this research, hope seemed to provide the lubricant for decision-making. Though trusting in the directives themselves as a representation of the healthcare system approach to respect autonomy, it was the action phase of these instruments that seemed to elicit the hope response either to have ACDs upheld (HCPs) or not to have to enact them (Ms F). The next chapter, Chapter Six, describes the final actions participants took on ACDs based on their knowledge, relationships and hope of preserving their personal autonomy in future healthcare and welfare decision-making.

### **Summary**

This chapter provided findings from this research and evidence from the literature that assessed the role of relationships in ACD decision-making. Theoretical development of these findings identified a number of factors participants contemplated in consideration of choice of SDM. These factors were described as themes and included: *having the discussion; the values of others; advocating for others; finding a SDM; who will decide for me; managing conflict; supporting the SDM; seeking sibling support; considering children, and faith, hope and trust*. These themes illustrated that choice of an SDM involved complex contemplation of the right person capable of acting for others in the manner anticipated.

Consideration of the SDM was influenced by the experiential knowledge of the participants. For those with HCP experience, factors of importance included: the willingness to be a strong advocate; the ability to understand the consequences to the participant of the decisions being made; and the strength to withstand the pressures of SDM decision-making. Healthcare professional participants in this research advocated for both patients under their care and family members, therefore their perspective was derived from multiple lenses generating greater contemplation of decisions to be made and choice of SDM.

From the LP perspective, the importance of these factors was less evident. For LP participants, factors of greater importance included being

able to act as SDM for parents and providing guardianship for children. Lay participants without in-depth knowledge of the healthcare system and the consequences of decision-making seemed to indicate that the values of the SDM chosen were of more importance in their choice of SDM.

Both HCP and LP participants experienced nomination of SDMs for themselves from two perspectives: being required to act as SDM for their parents whilst also considering guardianship arrangements for their children at the same time, reinforcing the perception that they are indeed, the sandwich generation. Considering SDMs from both of these perspectives at the same time was a complicated decision-making process for those whose family structures had tensions in relationships. Making sure that discussions were held about the choice of SDM and ACDs required were identified by participants as a way of managing these conflicts, though as evidenced in Chapter Four, these conversations were not always easy to have.

Finally, the emotional embodiment of relationships to ACD decision-making was described as having hope, faith and trust in those nominated to protect the participant's autonomy in healthcare and welfare decision-making. Healthcare professional participants had great faith in their own ability to carry through any ACDs they were responsible for as an SDM; however they had less faith in those chosen to act as their SDM in being able to do the same. Instead, they often described including additional support for their own SDM to bolster the hope and trust they placed in the SDMs ability to carry through with the ACDs. Lay participants revealed a different perspective of hope which indicated that they would not always be able to carry through ACDs entrusted to them as SDM and hoped not to be put to the test. Their perspective of hope was influenced by religious faith and trust in the healthcare system to provide means for overcoming death.

Participants applied contemplative knowledge to consideration of SDMs. Having thoroughly considered the qualities required for SDM decision-making based on experiential knowledge accumulated in their personal and professional life; it was anticipated that participants would

have completed some form of ACD or formalised SDMs. This was not the case, however.

Participants seemed to require even more motivating factors to help generate completion of ACDs. The next chapter describes another stage of contemplation participants entered before deciding on whether or not to complete ACDs, the stage of *Contemplating Actions/Inactions*.

## Chapter 6 - Identification of the Factors Influencing ACD Decision-making by SA Boomers – Part C

### Stage 3 - Contemplating Actions/Inactions

The third of the three stages of the BSPP of contemplation found in this research was that of *Contemplating Actions/Inactions*. This stage comprised properties participants identified as influencing their final contemplations in actually acting on ACD creation as described in Appendix 4. Findings in this chapter have been described in the same thematic format as Chapters Four and Five. Themes for Chapter Six can be seen in Appendix 5, Stage 3. Discussions of the elements that both enabled and prevented their completion of ACDs are described under the following themes.

#### ***I Know I Should, but I Haven't***

As evidenced in Chapter Five, participants contemplated and described how determining who should make decisions for them in circumstances which were neither desired nor controlled was emotionally difficult. This often led participants to acknowledge that they *should* do something for themselves, but either *had not* or had found it difficult to do so. Reasons provided for hesitating to engage in ACDs or substitute decision-making were often couched in the terminology of *scary* and *frightened* to describe their emotions when contemplating this issue as Ms E expressed in the following quote:

*It's not an easy topic to talk to people about because it's about making decisions... (doing my own) scared the living crap out of me, to be honest...I just have issues with the formalising...all those people out there that are non-supported (by wills or ACDs), that is scary...I guess you know the real world is that you just never know what's going to happen, do you? which is really scary...because I know what I'm in for, I personally believe that this (ACDs) is the only way to do it (Ms E).*

Her reflection of “I know what I’m in for” was a direct reference to her experience and knowledge of the ageing process, her family genetics, and the healthcare system itself. This knowledge was compounded by the emotional turmoil of having a conversation about ACDs and SDM with other family members who were unwilling to discuss ACDs for parents they no longer engaged with. Participants identified that trying to have ACD conversations with other family members could raise additional issues or difficulties in family relationships that might need to be overcome before the ACD or SDM could be formalised. To bridge this dilemma, participants identified that a more acceptable topic of conversation to open the door to ACD and SDM decision-making was that of organ donation, as illustrated in the following comments by Ms B and Ms C:

*You see, the organ donor thing is part of this in a way...if you're going to look at that (promotion of advance care directives), maybe you should be looking a little bit more at organ donation...I happen to have a lot of people in my circle that I could talk to about things like this...because organ donor is a key sort of thing that people think of and they might talk casually, 'oh, yes, I'd love my heart to go, or kidneys to go to somebody needing a kidney' but they don't actually take any steps to do it (Ms B).*

*It's (advance care directives) no different from organ transplants...transplantation has been one of the major things (for consideration of advance care directives) (Ms C).*

Participants such as Ms B and Ms C described how discussion of organ donation opened up the door to discussion of other topics associated with ACDs, including funeral arrangements and wills. Funeral arrangements were a topic of conversation that highlighted individual values and societal acceptance of discussion of death whilst wills were commonly expressed as a way of controlling distribution of assets. Discussion of funerals and wills often led to participants describing their witnessing of changes in society about death and dying. These discussions sometimes caused participants to decide not to act on ACDs.

### **Deciding Not to Act**

Some participants felt that discussion of funeral plans and wills with others was revealing enough to not need completion of formal ACDs to make sure these values were enacted. An example of this attitude was demonstrated by the comments of Ms D, Ms E and Ms F:

*I think that a verbal advance directive should carry as much weight as the written one but then again it's open to conjecture because if I did have a falling out with one of my daughters, they could ...make things more complicated...but I've told them this is what I want to happen to me should anything happen (Ms D).*

*(Husband) knows how I feel...he knows that I know how he feels (Ms F).*

*Verbally, it was always a contract between us – if anything happens to you guys, we'll take care of your kids and vice versa...but it was never formal and then once it was formal, it was like – it could really happen...We formalised ours, but they haven't formalised theirs (Ms E).*

Formalising these directives was a major barrier for some participants, even for those who subsequently created ACDs, such as Ms E. Without formal ACDs, participants understood that appropriate decision-making for them was at risk, yet still they hesitated in creating ACDs for themselves. This paradox was illustrated by participants through their use of the phrase “I know I should, but I haven't”. This phrase described the tension they felt in having in-depth knowledge of the need to complete these instruments but not actually wanting to do so as illustrated by Ms D:

*I suppose being in the health profession it sort of ... I feel I know enough about advance care directives that I, I don't personally need to be reminded to do them (Ms D)*

Ms D's resistance to completing the actual forms meant that she was willing to default decision-making to those in the future charged with her care, including HCPs or family members she may not have chosen herself. Employment as an HCP hindered the creation of ACDs for participants like Ms D who understood and trusted the system enough for it to act

appropriately for her. Analysis of patient decision-making in the United States revealed that many people preferred to leave the decision-making to the attending physicians (Collins, et al. 2006; Shalowitz, et al. 2007; Nolan, 2003). Nolan, et al.'s (2003; 2005) research found that patients preferred medical decision-making to be conducted jointly with their medical practitioner and that this decision-making should be independent of family when the person was conscious and competent. Contradictorily, patients in the same study preferred that when they were unconscious or not competent, the priority for decision-making should shift to family SDM decision-making over the medical practitioner. Participants in this research identified in Chapters Four and Five that when the decision-making shifted to SDMs, they faced difficulty making decisions without clear directives or being part of previous decision-making.

When participants did complete ACDs, they did so only because the formalisation process provided security that what they wanted done would be done. Formalisation was seen to be permanent whilst being able to dictate what they may or may not want to happen to them was a moveable feast, as expressed by Mr X:

*The fact that you could need it in terms of suffering some unfortunate event so perhaps you need to consider your own fragility of circumstances...to go there is almost a little bit unpleasant...because it's a piece of paper, it is completed, it does go somewhere and then to change it, or refine it, is I don't know, um, almost signing, yeah, there's a finality in paper, pen, lodgement...I've obtained the forms and looked at them and considered doing them but haven't taken that next step of actually concluding the module...if you could have the opportunity to...make adjustments, then it could be a growing and developing statement rather than something that is finite and no longer with you to change ( Mr X).*

Mr X's identification of the need to have flexibility in recording ACD decisions was based on both personal and professional experience of fluctuating circumstances requiring different decision-makers. These different decision-makers may be needed at different points of the dying or



decision-making process depending on care arrangements available and the ability of the SDM to handle the psychological and moral responsibility of acting for others at a time when the person they are representing is dying. Participants in this research expressed that it was at this stage that social support for those left behind could be wanting.

### ***Socialisation of Dying***

Reminiscing on the changing role of the socialisation of dying led several participants to describe changes in funeral practices they experienced in rural communities. These changed practices excluded those who were not closely related to the dead person by having private memorial services without enabling others to say their farewells. When this occurred, it prevented others from grieving and getting the support of their social networks in accepting and acknowledging the death. The South Australian Advance Directive Review (2008b) identified that for many people ACD decision-making was not just about healthcare or financial decisions, but also about social conditions of care, including support for those left behind to grieve. An example of how ACDs could assist in this process was that of people specifying who, what, when, where and how they wanted to pass their last days and dispose of their bodies after death (SAG, 2008b). In the past, there were set rituals for dying and death but these rituals have changed due to prolonged life and delayed death which influences not only the ability of people to take time away from their work to grieve, but also leaves many people living long after their own friends and relatives have died (Russell, 2010; Rubin, 2007; Gillick, 2006; ABS, 2002).

Gallagher (2009) discussed how longevity was distorting our old age milestones, including the acceptance of others' death and suffering as we aged. Gallagher (2009) illustrated this with statistics of the world's population of centenarians, which used to be nearly non-existent but will reach over 6 million people by 2050 at the current rates of longevity. Being 100 has been accepted by the public as the new "average" old age (Gallagher, 2009; Rubin, 2007; Gillick, 2006). This means that people are assessing 40 year-olds as 30 year-olds and 50 year-olds as 40 year-olds

(Gallagher, 2009; Gillick, 2006; Rubin, 2007). Not understanding when 'old' is really 'old' makes ACD decision-making even more difficult if people postpone making these decisions because they don't feel 'old'. This was evident for several participants in this research who indicated that they were just not ready to complete ACDs because they either did not feel old enough or ill enough to do so.

These changed perceptions of dying have promulgated the false belief in society today that medicine can cure all ills and created difficulties for HCPs sympathetic to the natural progression of the dying state. Accepting death often puts HCPs at odds with family members and patients who believe in miracles. Participants felt that if ACDs could be advertised and made friendlier, then it would be easier to persuade the public to accept the need for these instruments. In doing so, the public would be educated to accept ACDs as part of the reality of medical treatments that don't always end in miracles.

### ***Making ACDs More User Friendly and Timely***

Participants in this study suggested a number of different ways to make ACDs friendlier and to improve the uptake of ACDs even if participants had not completed these instruments for themselves. These suggestions included better promotion of the instruments through prominent people in the community discussing and advertising them. Many of the participants made reference as to how the media might be used to effectively promote and educate the public on ACDs, nominating television and radio advertisement as preferred vehicles. Other participants identified that participating in this research provided the impetus for them to engage or re-engage in contemplation of ACD creation as expressed by Mr Z below:

*Only started thinking about it after talking to you...where you are, where you are in your life at that particular time can influence you're thinking about the future (Mr Z).*

Time was described as an essential component of ACD contemplation by participants. Time was seen in several ways; the time

taken to access the documents; the time taken to complete the documents; and the time of life was amenable to thinking about the documents. Considerations of time were indicative of the social realities of communication and time management that existed for these participants. Putting ACDs on-line for completion was mentioned by all of the participants as a way of better managing time in relation to ACD completion. Mr X was particularly keen on this idea as evidenced in his statement below:

*You go onto the internet and you complete forms and they're lodged and there's a guided way through those and you have a record...It's recorded centrally so other people can tap in and know what's going on...you know all the privacy and security stuff taken care of that you can go in and make alterations as your preferences change, that people knew about it...I do think we've probably come to a stage where a lot more stuff can be done online (Mr X).*

Mr X's suggestions included using online facilities to create, register and adapt ACDs as conditions changed for the participant. Participants in this research described the ease and convenience that on-line communication could engender for creation of ACDs. Temel, et al. (2009) and Volandes, et al. (2009) identified the importance of an online environment for ACD contemplation, planning and implementation in the future. Volandes, et al.'s (2009) research provided evidence that educating the public with videos about the reality of disease states, such as dementia, could influence ACD discussions and management. Temel, et al.'s (2009) research emphasised how e-health records could encourage code status documentation. These research studies are only some of the many ways in which the online environments can assist ACD creation and management. Additionally, increasing online education in palliative care through websites such as Caresearch (2011) and Palliative Care Australia (2008) assists families, carers, patients, clinicians, educators and researchers to harness the information necessary to make informed and evidence-based ACDs. For those who were not computer literate, participants nominated local councils as a way to promote and advertise

ACDs. Within these venues, participants described how important it was to have expert advice and assistance when discussing and completing ACDs.

### ***Speaking to a Professional***

Jezewski, et al.'s (2007) research found that unless there was someone available to provide answers to questions about the person's choices and decision-making, completion of advance directives was less likely to occur. Education about the need for and particulars of ACD was essential in generating uptake of these instruments. Jezewski, et al.'s (2007) research found that educating the public about ACDs took one of two forms: didactic – based on educational information being distributed through pamphlets and at a distance, or interactive – using face-to-face methods of information distribution, answering questions, providing assistance and providing time to discuss the details involved. Their research found that it was critical that the person providing the information was not only knowledgeable but also provided the opportunity to discuss concerns.

The professionals nominated by participants in this research to support ACD discussion were people who possessed particular skills such as; medical knowledge of disease states, social worker knowledge of care packages, and legal knowledge of substitute decision-making. Healthcare professional participants suggested that professionals who met these criteria included nurses, doctors and social workers; whilst LPs and rural participants nominated their local general practitioner as an appropriate choice.

These professional groups were not the only professions that participants in this research felt could be helpful with ACD discussions. In fact, the first person all participants discussed ACDs with was a lawyer or solicitor because the ACDs were seen to be legal documents. Participants such as Mr X were aware however that witnessing of ACDs by lawyers could, at times, be superficial:

*People seek the assistance of lawyers, who from some experiences I've had there's not a lot of discussion...its sign here and that's it... (Mother) was able to go to a lawyer and simply lodge forms with no discussion taking place other than the completion of the forms, that was the discussion ...it seems a little too quick and nasty (Mr X)*

Nevertheless, all participants who had completed an ACD or a will seemed to have engaged a solicitor or lawyer at some stage of the process, as evidenced by Ms C who was on her way to the solicitor to create ACDs on the day of her interview. Engagement of a solicitor could be an inhibiting factor for those participants who were yet to complete an ACD with Ms D expressing cost as a factor to be considered. Nonetheless, expression of cost as an inhibiting factor was rare and not a reason given by participants in this research for not completing ACDs. Instead, participant knowledge of the legality of these instruments provided a means for standardised distribution and conduct in their completion. Jezewski et al.'s (2007) research identified that the majority of ADs completed in the US without professional intervention were not legal, however in Australia the Hunter v A decision (McDougall, 2009) discussed previously confirms that in Australia even ADs written on a piece of paper without being witnessed are still legally binding instruments.

Participants in this research identified that even with the level of knowledge they had about ACDs and SDMs, they still required professional support to discuss their own ACDs. Two participants, Mr X and Ms D, indicated that using doctors for this discussion, however, might not necessarily be right for them:

*Talking about it with a GP...but it's not purely a medical decision though, is it?...I mean GPs have a fairly high standing in the community but often the contact with GPs is fairly focused and driven along medical ills... I might see a GP once a year; maybe twice in a bad year...I don't see my GP that often...since I gave up smoking the contact with the medical profession has dropped right off (Mr X).*

*I don't go to the dentist, let alone the doctor (Ms D).*

These participant comments reflected the results of research by Bravo, et al. (2008) that found many people preferred to discuss ACDs with their family members rather than HCPs. To assist in the timely manner of these discussions, all participants in this research, including Ms D, suggested prompting people to engage with these instruments would be helpful.

Participants suggested that prompts should occur on particular birthdays or in line with particular documents, such as driver's license renewal, as illustrated by Mr X's comments below:

*If (that) someone posted something out for your 40<sup>th</sup> or 50<sup>th</sup> birthday...a prompt with your driver's license so you can throw it in the bin, um, superannuation...I do think linking it to some scheduled health check is reasonable but 75 seems a little too late, going into hospital seems a little too late (Mr X)*

Mr X's comments reflected what Ruff, et al. (2011) found in their study which suggested that engaging in ACD discussions over a long period of time from a younger age assisted and prepared consumers to engage in long-term decision-making.

The idea of prompting was linked by participants to the use of local councils for generating both the prompt and providing the service of professional advice on ACDs. One of the reasons that participants were keen to have councils involved in the process was because they associated local councils with other decision-making instruments used in the community, such as bush action plans as described by Ms E:

*We've got a fire plan (so ACDs are like that)...we've lived all our lives in some really volatile communities...It's probably more what we've been exposed to having both been in the country fire service, having both worked rural, having both been in law enforcement and nursing all our lives (Ms E)*

Ms E's familial experience of situations necessitating advance decision-making emphasised the important role that communities and councils can play in promoting and managing important planning

instruments such as ACDs. In particular, participants felt councils were well placed to provide prompt reminders to people to complete planning documents like bush fire plans and ACDs.

Throughout the interviews, participants displayed a willingness to engage with ACDs through a variety of methods and means but only did so when many of the factors cited throughout Chapters Four, Five and Six enabled the process of completion to be carried forward into action. Ultimately, in order to create their ACDs, participants identified that they needed to contemplate on many occasions over a long period of time considering many different factors before they were ready to create ACDs.

### **Summary**

This chapter described additional factors impacting on participants' in this research to either complete or not complete ACDs. These factors were described under the following themes: *I know I should, but I haven't; deciding not to act; socialisation of dying; making ACDs more user friendly and timely; and speaking to a professional*. What these themes illustrated was that it was not simple emotionally, intellectually or logistically to complete ACDs.

Nevertheless, participants identified throughout Chapters Four, Five and Six that completing ACDs required contemplation in stages reflective of knowledge, relationships and motivation to act. For example, Chapter Four, *Stage 1 – Contemplating Knowledge* demonstrated that combining awareness and experience of ACD use by others generated experiential knowledge and an understanding of the necessity of these instruments in the context of the participant's life. In Chapter Five, *Stage 2 – Contemplating Relationships*, participants identified how the choice of a SDM could be impacted upon by family relationships, conflict and communication which either promoted or negated further contemplation of ACDs for them. Finally, in Chapter Six, *Stage 3 – Contemplating Actions/Inactions*, participants identified additional factors that either promoted or hindered their final contemplation of whether or not to complete formal ACDs.

By the time participants in this research reached the third stage of contemplation, some had acted on their knowledge and choice of SDM to create ACDs (3 participants) whilst others were still contemplating formalisation of their decisions (4 participants). Reasons for non-completion of ACDs centred on: familiarity with the instruments through employment to the extent that conversations were preferred over formal documents; unwillingness to disrupt harmonious relationships by entering into a discussion that might cause conflict; and, time, accessibility and opportunity for discussion with professionals about the decisions to be made. Suggestions provided by participants to improve ACD uptake included: making ACDs available online, having professionals that could discuss ACDs knowledgeably with others, and being prompted to engage in ACD contemplation.

The impact of constantly contemplating future decision-making, either for themselves or others caused some of the participants in this study to forego completion of these instruments because of psychological and emotional exhaustion of what this decision-making would entail. For other participants, realistic acknowledgement of consequences that could occur without ACDs propelled them to complete these instruments to preserve their future autonomy. Participants in this research concluded that ACD decision-making was a continual process in their lives involving multiple stages of contemplation which never ended but forever haunted them.

Throughout Chapters Four, Five and Six, the BSPP contemplation has been described in its context of ACD decision-making for participants in this research. In the next chapter, Chapter Seven *Discussion and Conclusion*, the questions that have guided this research are answered through summarising the findings of Chapters Four, Five and Six in context with the BSPP of contemplation identified as guiding ACD decision-making by these participants. In addition, as a result of this research, a theoretical model is offered to explain the psychological process involved in the BSPP with recommendations for future use of this model to more fully develop the substantive theory of ACD decision-making by SA Boomers.



## **Chapter 7 – The Basic Social Psychological Process (BSPP) of Contemplation for ACD Decision-making by SA Boomers**

This chapter will discuss the emerging theory of SA Boomer ACD decision-making as revealed by the BSPP of contemplation.

Contemplation refers to the ‘act of the mind in considering with attention; the act of thinking about something intently’ (McKechnie, 1979b, p. 394). Contemplation was established as the BSPP which guided participants in this research in their behaviour and practice of ACD decision-making

The discussion in this chapter addresses, very briefly, the content of the contextual literature review from this research that examined the historical, ethical, legal, psychological and sociological developments occurring throughout the maturation of the Boomer generation in parallel with development of ACDs. Throughout this discussion, reference is made to particular elements that may affect South Australian Boomers.

Following this discussion, a possible model for elaborating on the psychological process of ACD decision-making by participants in this study is introduced, namely The Transtheoretical Model (TTM) by Prochaska and Velicer (1997). Prochaska, et al. (1992) developed this psychological therapeutic behaviour model to elucidate the manner in which sociological and psychological behaviours combine to influence health risk behaviours. Extrapolation of this model to ACD decision-making by participants in this research is described for future research on this topic to test the preliminary substantive theory described in this study. To conclude the chapter, recommendations for future education and promotion of ACDs to the SA public, particularly Boomers, are described.

### ***The Context of ACD Decision-making for a sample of SA Boomers***

To begin the discussion, the purpose of this research was to provide insight into the factors that influenced advance care directive (ACD) decision-making by a sample of South Australian Baby Boomers. The

reason for researching this topic was to assess the uptake and understanding of these instruments by the generation that helped create them as a means of preserving their future autonomy in healthcare and welfare decision-making. This research was performed through exploring the historical, ethical, legal, psychological and social elements of ACD decision-making in the literature and comparing these findings with a sample of seven South Australian Baby Boomers. This comparison was made to understand the influence that these elements may have on future development and use of ACDs and ACP for this population.

To begin this research, the contextual literature review explored the historical development of these instruments. Advance care directives were developed by and during the maturation of a generation known in democratic societies as the Boomer generation. These instruments were the legislative embodiment of personal choice in healthcare and dying and were developed as a response to the advent of medical technologies that prolonged life and delayed death. In many ways, ACDs were the manifestation of the Boomer generation's hope to wrest control from this plethora of medical technological advancements (Bradley, et al. 2011). The advent of these instruments in democratic countries coincided with a time of great social upheaval of traditions and customs that demanded individual choice in all areas of life, including the manner in which people lived and died.

Now, the first of the Boomers have reached an age (identified politically, economically and socially as *retirement age*) in which future considerations of healthcare and welfare have become more prominent for them (Humpel, et al. 2009). Considerations at this time often require contemplating putting plans in place for financial and care management in the future. Instruments in South Australia designed to assist with this planning include, but are not limited to, the: EPA – Enduring Power of Attorney for financial decision-making; EPG – Enduring Power of Guardianship for healthcare and welfare management; MPA – Medical Power of Attorney for healthcare decisions only; Anticipatory Directive – instructions for care that indicate the QOL acceptable to the person; and, the Will – which determines how assets and guardianship should be

distributed after death (OPASA, 2003) . In South Australia, specific care decision-making ACDs are the EPG, the MPA and the Anticipatory Direction (OPASA, 2003).

Advance care directives were specifically targeted for this research because they exemplified the range of healthcare and welfare decision-making that defines the consumer choice ideology of the Boomer generation. Therefore, the intent of this research was to see if South Australian Boomers were using these instruments for themselves as evidence that this consumer choice ideology is guiding their future care decision-making.

To understand whether and how SA Boomers have been influenced by their contextual inheritance of ACDs, this research used the qualitative research method of classical grounded theory to enable an in-depth exploration of the subjective experience of this phenomenon to determine the *why* and *how* a sample of SA Boomers engage with ACDs. Investigating the subjective rather than the objective social and psychological processes impacting on this group's decision-making revealed differences in the way this group of participants evaluated and utilised ACDs in comparison to other groups (e.g. frail elderly and terminally ill) previously studied. The issue of longevity is one such factor that distinguishes future decision-making for Boomers in comparison to the decision-making of previous generations. Longevity has created whole industries catering to the care of the increasing number of elderly whose families are unable to look after them – an expectation that would have been the norm during the maturation of these elderly (Rubin, 2007).

Families may be unable or unwilling to care for elderly relatives due to their own ageing issues, for example chronic illness, lengthier employment, children still at home compounded by the increased longevity of themselves and those they become responsible for. In the event of these circumstances, Boomers, as suggested by some participants in this research, may decide not to face the responsibility of care associated with illnesses that have long dying trajectories such as dementia. In support of this trend, many Boomers who have been acting as SDMs, including those in this sample of SA Boomers, have been moving elderly relatives into

residential aged care facilities in greater numbers than ever before (AIHW, 2010c). Doing so has necessitated family members, the healthcare profession and governments to assess the equitable and sustainable use of healthcare resources for this growing population into the future especially as the Boomers themselves age and require similar care (PC, 2011). This has challenged the ability of governments to provide the same level and choices of healthcare services to the Boomers that their parents currently experience.

Australia has not been immune to these developments and has responded by increasing opportunities for Australians to engage in advance care decision-making (TCTEPC, 2011). South Australia particularly has been influential in leading the way on adoption of ACDs and advance care planning (ACP) through legislating the Natural Death Act of 1983 followed by The Consent to Medical Treatment and Palliative Care Act (1995). These Acts recognised that death was a natural product of life and that people had the right to choose dying and death over continuous medical treatment that prolonged life at the expense of quality of life (QOL).

Though the Consent Act legislation in South Australia is very succinct, it has not catered for the current state of medical technological advancements which have blurred the boundaries between living and dying such that resultant QOL is questionable and death may be preferred (Bensch & Wood, 2009; Teno, et al. 2007; Higgs, et al. 2003). For healthcare professionals and the lay people of the SA Boomer generation, observing the consequences of unwanted or poor quality medical treatments on their loved ones engendered contemplation in this sample of SA Boomers about what they would choose for themselves if and when they may be placed in a similar situation knowing that they have the right and, indeed, the mandate to make different choices.

To understand what people born in the Boomer generation might choose to do this research investigated how a sample of SA Boomer decision-making on ACDs differed from previously studied demographic groups found within the literature. This comparison was made because

much of the previous literature on ACD use and implementation has focused on the terminally ill or frail aged (Wilkinson, et al., 2007).

Notwithstanding the lack of specific evidence of ACD use by Boomers, differences between the generations in utilisation of ACDs have been hinted at in the literature. For example, recent studies have indicated that the general public (Ruff, et al., 2011) and those of the Boomer generation and beyond (Humpel & O'Loughlin, 2010) have begun to change their moral values on issues such as health, life and death such that they accept that planning for the future is a necessity. However, most of this research has not focused on the individual who has actually completed an ACD, rather the information has come from the HCP, carer or family perspective often because ACDs have been studied retrospectively (Durbin, 2011; Khodyakov and Carr, 2009; Chan, 2004). Assessing ACD use at this time has limited the information available on the actual effectiveness of these instruments for times of acute physical or psychological illness where a person may recover and regain control of their decision-making and can determine whether their ACDs were enacted in the way anticipated. Research in this area of ACD use would be able to better inform others of the effectiveness of these instruments for advance care decision-making from the perspective of a relatively healthy person who may become temporarily incapacitated due to chronic illness over a long period of time. This is a scenario most Boomers are likely to face in the current social context of healthcare.

Many of the contextual issues highlighted previously in the literature such as, age, health status and having discussions with others about advance care instructions (Reuben, 2009; Brown, 2002; Tinker, 2002) were also contemplated by participants in this study. However, the research conducted in this study of SA Boomers provided unique insight into a group of people contemplating ACD creation who were healthy without any underlying pressing need to create ACDs but contemplated completion of them nevertheless because of their experiences of others with and without ACDs. This perspective differs from other demographic groups studied in the literature where creation of ACDs was typically done

because of frail age or illness necessitating ACP for hospitalisation or accommodation in a nursing home (Bravo, et al. 2008; Wilkinson, et al. 2007; Layson, et al. 1994).

Another factor distinguishing ACD decision-making by Boomers in this research was the number of participants with experiential knowledge of the consequences of these factors through their employment in the healthcare industry. This employment, in addition to family substitute decision-making (SDM) responsibilities, has meant that Boomers in this research were not passive recipients of medical technological advancements but actively contemplated which medical interventions they would choose to have or not have for themselves in the future. Contemplation of ACD decision-making in the Boomer context required thinking of these instruments in stages that were not linear but often flowed back and forth as different situations and contexts requiring consideration of ACDs arose. At each stage of this contemplation a number of factors were identified that either enabled or inhibited further contemplation or action on ACDs.

As an example of this deliberative process, during the first stage of contemplation identified in this research, *Contemplating Knowledge*, participants expressed their awareness of the need for ACD decision-making through observation, experience and knowledge that encompassed the ethical, legal, psychological and sociological understanding of these instruments. These combined elements of knowledge created experiential knowledge of the current practices of ACD use as seen through the lives of others.

Through employment as HCPs as well as acting as SDMs for members of their own families, healthcare participants observed the stress involved in making decisions for those in a profoundly diseased or dying state. During these observations, HCPs noted that SDMs were often inexperienced with disease, death and the dying process and the decisions they made for the person they represented were sometimes questioned by HCPs as the right decisions for the patient. This questioning was shown in the literature to undermine the confidence of both HCPs and SDMs and could generate conflict between HCPs and

family members. For HCP participants in this research, when presented with the above situation, they often adopted an advocacy role to ensure patient requests were enacted as anticipated.

To prevent conflict, healthcare participants in this research said that good communication skills were required by the medical practitioner to engage family SDM decision-making in a timely manner where values of the patient could be elucidated and subsequently respected. When participants witnessed medical practitioners with good communication skills, the resulting experience was a positive one for all concerned. Negative communication skills, however could result in participants witnessing episodes of conflict, disagreement or poorly informed decision-making bringing into the forefront the ethical value of ACDs (e.g. protection of personal autonomy). Negative experiences of healthcare and welfare decision-making were motivating factors for participants to contemplate creating their own ACDs to protect their future QOL if similar circumstances were to arise for them.

Experiential knowledge of ACD decision-making highlighted the positive and negative psychological effects such that, in essence, participant intent for contemplating these instruments shifted from protecting others to protecting themselves. For LP participants in this research who lacked healthcare knowledge and experience of the consequences of healthcare decision-making, they did not express as strongly the need to act as advocate for others or themselves in the same way. Instead, there was an indication that ACDs for these participants represented a way of providing guardianship arrangements for minor children or elderly parents that would be respected by others rather than preserving QOL for themselves. However, within this research, it's not possible to generalise whether this would be applicable to other contexts or sample groups.

Gaining respect from others for legitimacy of guardianship or SDM decisions indicated another level of contemplation for these participants, *Contemplating Relationships*. At this level of contemplation the importance of communication was re-emphasised, this time from the perspective of the SDM. This perspective was acknowledged by participants in two ways:

first, in their role of acting as the SDM for others; and, second, in needing to choose an SDM for themselves. At this stage of contemplation, participants described that the choice of SDM in both situations was critical to the successful implementation of ACDs and a positive patient/family/HCP experience with the SDM needing to be supported and respected in the decisions made.

All participants who volunteered for this research had acted or were currently acting in the role of family SDM for others, principally their parents. Participants acting as the SDM for others provided both negative and positive assessment of ACD use, principally because the choice and actions of the SDM could result in tension between family members if values and decisions had not been communicated to other family members. Participants also described how family tension could be impacted by the composition of the participants' families. The composition of their families identified another important difference between the Boomers and other generations with regard to choice of SDM. The family structures for participants in this research revealed that only 28% of the participants were currently in a 'nuclear' type family of mother/father and two children (ABS, 2006b; 2006d). For those participants not within a nuclear family structure, the other types of families described included step-families, adoption and those without children. Under these non-nuclear family structures, choice of a SDM who could understand and respect the other person's values was seen as difficult.

Of interest in this research was the fact that none of the participants chose a sibling to be their SDM and reasons described for this were lack of responsibility of the sibling for parental decision-making or dysfunctional relationships with siblings. When siblings were not chosen, participants with adult children but without spouses chose one or other of their children explaining that they chose the child they felt would be best equipped to handle the stressful situation they would be under and capable of actually enacting the ACDs of the participant.

Those participants with minor children contemplated ACDs from the perspective of guardianship for their children. Acting from this perspective established another unique character to Boomer ACD decision-making,



recognising that ACD contemplation for this *sandwich generation* meant contemplating choice of SDM for their parents at the same time as considering SDMs to protect their children's and their own interests.

Participants with spouses typically chose their spouse unless there were religious or cultural considerations preventing this and this became a particular issue for one participant whose spouse was from another cultural background. Without children and a spouse who would not enact the participants ACDs, it became problematic for this participant to identify who else could be chosen to act as his SDM. The one participant in this study without children or a spouse chose her parent as her SDM leaving this participant in a vulnerable position of having no one representing them if their parent died before them as well as being subjected to the values of a different generation, namely her parent.

Participants who witnessed the outcomes of healthcare and welfare decision-making for those without an SDM were profoundly disturbed by the poor QOL that resulted. This compelled some healthcare participants to act as advocates for those in this situation and created another depth of knowledge reflective of the difficulties in conducting ACD decision-making when the SDM was in the dual role of HCP and SDM at the same time. This knowledge was enough to spur most participants into verbal discussion with family members about ACDs and/or formalisation of decisions made by the participants and constituted the third stage of Contemplation, *Contemplation Actions/Inactions*.

Actions that participants undertook with regard to their own ACDs were confusing as their understanding of actual ACD terminology was flawed. Confusion in ACD terminology was found in the literature to be a major inhibiting factor in their use (Brown, 2006; Brown & Jarrad, 2005b). Nevertheless, when further clarification took place with participants in this study, what was established was that all participants had created Wills and all but one had created EPAs. However, EPAs and Wills are not ACDs. Only three participants had actually completed the ACDs of EPG, MPA and/or anticipatory directions. Some participants (Ms E and Ms F) identified that the only reason they knew about ACDs was because during the creation of their Will, their solicitor/lawyer had asked them to complete

them. Participants indicated that without this professional help, they would most likely have not completed the instruments.

Discussion of Wills and ACDs initiated contemplation of organ donation, funerals and the differences between dying today and dying in the past. What rural participants, in particular, indicated was that there was less support on offer today for those grieving the loss of community members who were not close relatives. Additionally, participants indicated that previously dying involved a matter of days or weeks before death took place rather than the months and years of today. This prolonged life and delayed death made ACD decision-making emotionally, physically and psychologically exhausting. These emotional factors prohibited completion of ACDs by some of the participants, especially if there was religious or cultural conflict with the SDM of choice.

To overcome such inhibitory factors, participants eagerly offered a number of suggestions to help those who had not yet completed or contemplated ACDs. These suggestions included; on-line accessibility, knowledgeable assistance from a professional; advertisement and education on ACDs through the media and local council; and, most importantly, being prompted to complete them. Prompts were considered a positive enabler for both contemplation and completion of ACDs. Participants suggested that prompts should be initiated at special occasions, such as significant birthdays (most participants thought 40-50) or renewals of driver's licenses (associated with organ donation).

In summary, this chapter provides important insight into how a sample of seven SA Boomers' understanding of the context of historical, ethical, legal, psychological and sociological contemplation of ACDs has contributed to their actions on ACD decision-making. The manner in which these participants have understood ACDs illustrates the basic social psychological process (BSPP) of contemplation in their approach to this subject. To test whether this approach is the same for others in a similar context, a hypothesis has been formulated to test the BSPP. Specifically, if actions such as prompts in an online environment are provided to the SA public, including Boomers, to engage in ACD completion, then an increase in uptake and completion of these

instruments should result, particularly in the Boomer generation demographic. Testing the BSPP with this hypothesis will enable further development of a substantive theory on this topic.

### ***Testing of the BSPP***

The contemplative act of ACD decision-making by participants in this research revealed all participants in this study were prepared or ready to engage in this action when all of the right variables were in place for them to do so. This research identified that both sociological and psychological elements influenced stages of contemplation that either enabled or inhibited action in ACD completion. By comparing results of this study with similar studies, albeit different demographic groups and contexts, Glaser and Strauss (2008/1967) suggested conceptualisation of the BSPP occurring within the context of the phenomenon being studied could be further delineated. Conceptualisation enables theoretical frameworks to be revealed from the literature that can assist evolution of theoretical sensitivity from this study into the next stage of the CGT process; a testable theoretical hypothesis to explain both the behaviour and practise of people in the context being studied (Glaser, et al. 2008/1967; 1978).

Theories in the psychological literature that touch on various elements of contemplative action have generally focused on religious elements of meditation and mindfulness practice (Sherman & Siporin, 2008). Meditation theories focus on a therapeutic process of intentionally thinking about an action, the results of an action, or one's self in relation to these actions to generate outcomes desired (Sherman & Siporin, 2008). On the other hand, social theories of behaviour concentrate on how people behave in their social environment in relation to the many features they encounter in this environment (Germov, 2009). This research study identified that although contemplation of ACDs is based within the societal context of factors influencing contemplation, the actual act of completing ACDs rests in the psychological influence that promotes engagement to act. In consideration of these competing, yet complimentary features of decision-making, the next section of this chapter describes the application of a psychological model, the Trans Theoretical Model (TTM), to further

delineate the social and psychological factors enabling or inhibiting ACD decision-making by SA Boomers.

### ***Application of TTM to the BSPP of Contemplation in Future Research***

The Trans Theoretical Model (TTM) developed by Prochaska and Velicer (1997) was developed for those with addictive behaviours who were not being helped by current treatments. The model was developed to try to break the cycle of addiction (most of the literature in this area focuses on smoking cessation) through understanding, on the population level, the motivating factors that would help change risky healthcare behaviour previously non-amenable to change (Prochaska, 2006).

The TTM model is comprised of five stages that identify when a person is ready to address their addictive behaviour as well as when they are prepared to act on it. The first stage of TTM is *pre-contemplation* and is defined as the stage where a person is unaware of health risks and no thought of change is forthcoming. The second stage is *contemplation* – in this stage the person is aware that their behaviour may endanger their health and thinks about doing something about it but is not ready to do so. In the third stage *preparation*, the person is aware and understands the behaviour and its consequences such that they are now willing to change their behaviour by preparing to cease or develop the action under consideration. The fourth stage – *action* – is when interventions to assist a person to change their behaviour are most effective as the person is ready and willing to participate in the behaviour change. In the final stage – *maintenance or termination* - the person continues the desired behaviour or ceases any interventions meant for a limited duration (Barkway, 2009)

The manner in which the 5 stage TTM model could test the BSPP from this research on Boomer behaviour in ACD decision-making is:

1. TTM stage 1 – *pre-contemplation* – Boomers who do not perceive the need for ACDs or are ambivalent about completing them do so through a lack of knowledge or experience about the consequences of not completing an ACD. This aspect may apply largely to the lay public without HCP experience or intimate care experience or exposure to the healthcare system and the medical

interventions on offer. Participants in this research suggested large scale educational and advertisement efforts would increase public knowledge of ACDs and the consequences of not having these instruments in the event of a medical emergency. These educational and advertisement efforts would not only generate the stage of pre-contemplation for ACD completion but would also create the first stage of contemplative knowledge necessary to initiate contemplation or action on ACDs. Measurement of the effectiveness of this experimental intervention could be evaluated through surveys and file data on completion of ACDs with a particular focus on Boomer completion rates.

2. TTM stage 2- *contemplation* - this stage of the TTM model actually applied to all of the participants in this study and was represented through their volunteer efforts to participate in this research. Volunteering to participate in this research also represented a sufficient level of contemplative knowledge about ACDs to change ambivalence and enact curiosity about these instruments.
3. TTM stage 3 – *preparation* – for participants in this research, they showed they had reached this stage of ACD decision-making when they made preparations to engage a SDM. Choosing a SDM required contemplation of the relationships with others in their lives. Often, participants discussed their contemplation of SDM in the context of who to nominate in a Will. To assist the public to successfully engage in the creation of ACDs and not just Wills, participants in this research suggested providing knowledgeable professionals who could educate the public about ACDs. This educational effort would make it clear that ACDs are not Wills, would encourage ACD completion and address any concerns an individual might have about these instruments and the duties associated with acting as an SDM or executor.
4. TTM stage 4 – *action* - this stage of the TTM model requires the person to take action on the behaviour or practice they have been contemplating. Actions undertaken by participants in this study

were identified in the Contemplation Actions/Inactions stage in this research study where participants either actioned completion of ACDs or chose to continue contemplating them. Many participants in this research suggested that to assist them to action ACDs rather than continue contemplating them, it would be helpful to place these instruments online for ease of use (both in time and practice) as well as prompting individuals to complete them on significant occasions. In addition, participants suggested that the terminology in the ACDs be in a language accessible to the lay public rather than in legal language which is difficult to understand.

5. TTM stage 5 – *maintenance or termination* – for most participants in this study there was no clear indication as to whether they had reached this stage with their own ACDs though the composition of the stage Contemplation Actions/Inactions suggested participants would revisit their completed or needed ACDs as time and circumstances dictated. Maintenance or termination would suit the purpose of ACDs as they are living documents to be amended and revised as life circumstances change and are of no further use when a person has died (excepting of course for organ donation instructions).

### ***Recommendations for Future Research***

Therefore, in consideration of the final objective of this study, i.e. recommendations for future research on this issue, the following suggestions are recommended:

1. A larger study of what ACDs mean to other Boomers in other states and territories within Australia given the variability in terminology of instruments and what they imply;
2. Research into the most successful methods for educating healthy people on ACDs. This research may elucidate differences in understanding between the lay public and HCPs on ACDs;
3. Research into developing, implementing and evaluating online sources of ACD use for healthy people, especially Boomers, to

- determine the quality of online educational efforts and willingness to engage with these instruments in an online version;
4. Improved census data collection on supportive relationships within family structures or otherwise to identify who possible SDMs will be for the Boomers;
  5. Research into the possibility of linking guardianship arrangements for children with ACDs for their parents;
  6. Research into the possibility of involving local councils in ACD prompting and provision of professional services accessible to the public for ACD support and completion;
  7. Research into what happens when an otherwise healthy person's ACD is activated at a time of acute medical crisis and the outcomes arising for that individual afterwards;
  8. Future presentation of research into this area should delineate the differences between generational cohorts within the research being conducted;
  9. Research into whether government policy on this issues encourages or inhibits the uptake or otherwise of ACDs.

To assess the effectiveness of future research, a rigorous evaluative process is recommended that will incorporate the many sociological and psychological factors influencing the motivation for ACD creation by healthy Boomers.

### ***Conclusion***

This sample of seven SA Boomer participants has provided important insight into the impact of witnessing QOL and QOD of others. Medical interventions and/or aged care accommodation has left lasting impressions on most of the participants that have engendered them to contemplate what they would want for themselves if ever placed in a similar situation. Participant contemplation of these scenarios was acknowledged as continuing over many years as experiential knowledge was built up through professional and personal experience of substitute decision-making for others. Healthcare professional participants in this study, through their employment in the healthcare system, were able to

gain a more realistic assessment of the consequences of healthcare and welfare interventions witnessed. Lay participants, on the other hand, without this additional knowledge expected medicine to not only determine QOL but also delay death.

These contrasting areas of knowledge meant that some of the Boomer participants in this study hesitated to engage with ACDs if they could not reconcile their own mortality. Non-reconciliation with the inevitable was exacerbated by the continued promotion of medical interventions that delayed ageing. This made it difficult for this sample of Boomers to know when they were truly 'getting older' and needed to think about planning for the future. Additionally, the promulgation of miracle rescues through the media and medical professionals meant that for some of the Boomer participants in this study, traumatic health or welfare events would not lead them to consider what should be done for them in these situations as they expect to be cured and returned to their previous state. Nevertheless, those participants in this study who did accept their own mortality were still subject to more pragmatic considerations of time, knowledge, and accessibility before completing ACDs.

To gain a greater depth of knowledge of the psychological and social factors that could motivate behaviour change in this generation to practice more timely completion of ACDs, this research proposed the TTM theory to test the BSPP emerging from this study and provide a model to guide future research. Future research recommendations made incorporated developing, implementing and evaluating the use of ACDs by the Boomer generation in a manner which would make the instruments more accessible and useable for all Australians.

Informed decision-making based on personal choice has been the hallmark of the Boomer generation. The seven participants in this research gave us important insight into ideologies, knowledge and experience of ACDs that indicated they had reached a stage of life necessitating contemplation of these instruments to preserve their future autonomy in healthcare and welfare decision-making. The decisions that individuals, such as those in this research, make regarding their future healthcare planning will have implications for government policy, including the



promotion of ACDs that warrant consideration. Changing “I know I should, but I haven’t” to “I knew I should and I did” will indicate that Boomers have embraced their coming of age in the revolutionary spirit that defines them.

## **Appendices**

## Appendix 1: Glossary of Terms relating to Advance Directives in South Australia

Advance Directive (AD)	In South Australia, this term is now being used to specify the Enduring Power of Attorney only.
Advance Care Directive (ACD)	A general term for statutory instruments that enable a competent adult to support their wishes, instructions or decisions about health, life-management or financial affairs are known and acted. These instruments can also appoint a substitute decision maker.
Agent	A general term for a person legally appointed by an individual as their substitute decision-maker for health, life-management or financial decisions.
Agent Advance Care Directive	An advance directive that appoints an agent to make decisions during times when capacity is lost or diminished. This is an example of an Advance Care Directive.
Personal Advance Directive	An advance directive that does not appoint an agent, but records instructions and wishes about health care and life-management for future times of lost or diminished capacity. This is also an example of an Advance Care Directive.
Advance Care Plans	Advance care planning is a process whereby individuals in consultation with health care providers and relatives, describe their personal values and life goals and put in place advance care plans for their future health care, in case they become incapable of making such decisions personally at a later time. There are multiple versions of this instrument: <i>The Good Palliative Care Plan</i> (Palliative Care Australia, 2008) and the <i>Statement of Choices</i> (Austin Health, 2006) which act as anticipatory directions in palliative care and advance care planning programs, respectively. In addition, there are <i>Ulysses Agreements</i> in Mental Health care planning (Srebnik & LaFond, 1999; Srebnik & Russo, 2008) and the <i>Life Values Statement</i> (South Australian Voluntary Euthanasia Society (SAVES), 2010) produced by the South Australian Voluntary Euthanasia Society which defines unacceptable circumstances that would be worse than death itself to help guide medical decision-making.
Anticipatory Direction (Ant Dir)	This is an instructional document and in other localities is known as a 'living will' (Wilkinson, Wenger, Shugarman, & Rand, 2007) In South Australia, this instrument only comes into effect when the end of life is near and records the treatment a person wants or does not want in the terminal phase of a terminal illness or in a persistent vegetative state (PVS).
Capacity	The measure of a person's ability to make personal decisions or to make a particular personal decision.
Competence	A legal term used to describe the mental ability required for an adult to sign a legal document while understanding the consequences of his or her decisions.
Enduring Power of Attorney (EPA)	This is the most commonly known Advance Care Directive. This instrument nominates a surrogate to make decisions on financial/legal matters only but its application is often extended into other areas of care.

Enduring Power of Guardianship (EPG)	This Advance Care Directive nominates a surrogate who can refuse or consent to medical treatments as well as health care, more generally, that involves other health professionals. In addition, the surrogate can also make lifestyle decisions, which include, but are not limited to – residential, employment and holiday arrangements and particular instructions can be written to inform the substitute decision-maker of other requirements and/or how the instructions should be interpreted.
Healthcare Professionals	Health professionals include medical, dental, nursing, social work, ambulance paramedics and allied health staff; these are often called clinicians.
Life-limiting condition	A disease, condition or injury that is likely to result in death, but not restricted to the terminal stage when death is imminent.
Life-management decisions	Decisions about personal matters such as residential arrangements, employment, holidays, visitors and care of pets; these are separate from health care and financial decisions.
Life-sustaining measures	Treatment that sustains or prolongs the operation of vital bodily functions incapable of independent operation, including assisted ventilation, cardiopulmonary resuscitation, and artificial hydration and nutrition.
Medical Power of Attorney (MPA)	This Advance Care Directive nominates a surrogate who can refuse or consent to medical treatments.
Medical treatment	Administration of therapy by either physical, surgical or psychological means, or administration of medications to prevent disease, to restore or replace body function in the face of disease or injury, or to improve the comfort and quality of life. Medical treatment can be administered by a range of health professionals.
Palliative care	An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems (e.g. physical, psychosocial and spiritual). Palliative care intends neither to hasten nor postpone death but provides relief from pain and other distressing symptoms affirms life and regards dying as a normal process.
PVS or persistent vegetative state	PVS was recently redefined by the National Health & Medical Research Council as post-coma unresponsiveness to differentiate persistent vegetative state from minimally responsive state (National Health & Medical Research Council, 2003)
PCU or post-coma unresponsiveness	PCU is defined as a state or condition in which a person has emerged from coma to the extent that he or she has sleep/wake cycles but with no observable, purposeful responses to stimuli.
Prescribed treatments	Procedures that currently require Guardianship Board approval when provided to adults lacking capacity; limited to ECT (electroconvulsive therapy), sterilisation, termination of pregnancy and neurosurgery for mental illness.

Relatives	Used broadly to include close family members of the person as well as someone overseeing the ongoing day-to-day care and well-being of the person (but not a paid carer)
Representatives	Legally appointed decision-makers, including agents appointed by the person and guardians and administrators appointed by the Guardianship Board
Terminal phase of a terminal illness	Terminal illness means an illness or condition that is likely to result in death; and terminal phase of a terminal illness means the phase of the illness reached when there is no real prospect of recovery or remission of symptoms (on either a permanent or temporary basis).
Ulysses Agreement	A record of an agreement between a patient, their psychiatrist, relatives and others, about treatment to be provided and arrangements to be made during future episodes of mental illness.
Legislation supporting ADs and ACDs	QLD – Powers of Attorney Act 1998 and Guardianship and Administration Act 2000 SA – Consent to Medical Treatment and Palliative Care Act 1995 VIC – Medical Treatment Act 1988 WA – Guardianship and Administration Act 1990 and Acts Amendment (Consent to Medical Treatment) Act 2008 ACT – Medical Treatment (Health Directions Act) 2006 NT – Natural Death Act 1988 (Kerridge, Lowe, & Stewart, 2009b)

(South Australian Government, 2008b)

## Appendix 2: Codes, Categories and Stages

**Open, Substantive** and **In Vivo** Codes. Sub= Examples of substantive code from researcher; In Vivo = examples of verbatim code from participant, all others Open coding reflective of either substantive or in vivo.

Code Name	Sources (No of Participants Expressing This Code)	References (No of Times Code was expressed across all interviews)	Stages Applied to: (Contemplating Knowledge – CK; Contemplating Effective Relationships - ER; Contemplating Actions/Inactions- C A/I)
Abuse	4	12	CK
Accessibility	2	7	CER
Actions Taken - <i>Sub</i>	6	671	C A/I
Advance Directives – <i>In Vivo</i>	7	511	C A/I
Advice (Provided and Provided To)	4	79	CK
Advocate	4	60	CK
Age - <i>Sub</i>	7	162	CER
Awareness – <i>In Vivo</i>	6	957	CK
Capacity and Competence	4	18	CK
Carers/Caring - <i>Sub</i>	7	125	CK
Clients	4	61	CK
Communication - <i>Sub</i>	6	734	CER
Community	5	86	CK
Computer	4	23	CER
Conflict	4	48	CER
Contemplation - <i>Sub</i>	4	164	CK
Content Knowledge of AD - <i>Sub</i>	6	159	CK
Continence	1	3	CK
Control	3	29	CER
Culture	6	177	CER
Death and dying – <i>In Vivo</i>	6	180	CK
Decision-making – <i>In Vivo</i>	7	781	C A/I
Dementia	5	21	CK
Dignity	1	2	CK
Education	6	169	CK
Emotions (Fear, Sadness) - <i>Sub</i>	7	579	CER
Employment - <i>Sub</i>	7	102	CK
Environment - <i>Sub</i>	4	29	CK
Euthanasia	3	10	CK
Experience – <i>In Vivo</i>	7	923	CK
Finance	7	78	CER
Forms - <i>Sub</i>	4	103	CER
Funerals	5	30	CK
Government Policies	7	58	CK
Guardianship Board - <i>Sub</i>	5	24	CK
Health- <i>Sub</i>	7	293	CK

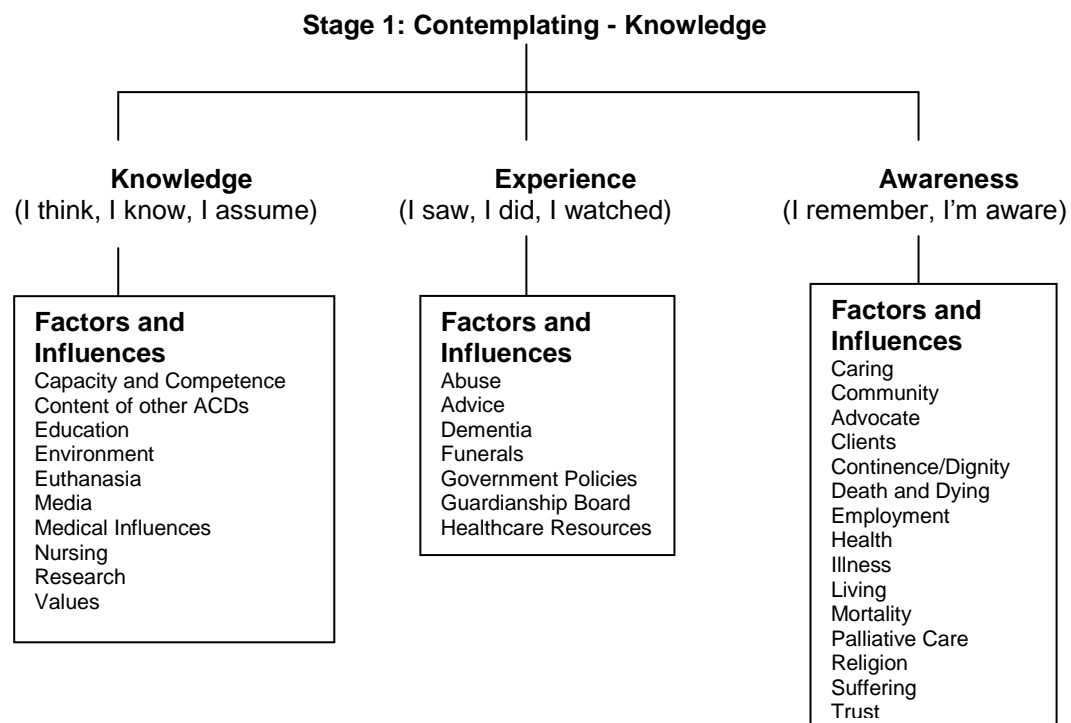
Healthcare Professionals - <i>Sub</i>			CK
Healthcare resources - <i>Sub</i>	6	201	CK
Hope	2	8	CER
Humour	1	1	CER
Illness - <i>Sub</i>	7	270	CK
Influences - <i>Sub</i>	7	198	C A/I
Knowledge - <i>Sub</i>	7	1273	CK
Language	3	8	CER
Legal Requirements - <i>Sub</i>	7	281	C A/I
Limitations	3	19	CER
Living	4	16	CK
Location - <i>Sub</i>	7	207	CER
Media	4	22	CK
Medical Influences - <i>Sub</i>	6	205	CK
Mortality – <i>In Vivo</i>	3	11	CK
Nursing	4	22	CK
Organ Donation – <i>In Vivo</i>	4	27	CER
Palliative Care	3	16	CK
Privacy and Security - <i>Sub</i>	2	5	C A/I
Professionals - <i>Sub</i>	6	437	CER
Quality of Life	6	111	CK
Residential Aged Care Facility	5	53	CK
Relationships - <i>Sub</i>	7	1362	CER
Religion	4	49	CK
Research	6	17	CK
Responsibility – <i>In Vivo</i>	6	426	C A/I
Retirement	2	4	CER
Revision	2	4	CER
Risk	5	42	C A/I
Suffering	3	30	CK
Support	2	17	CER
Time	7	634	CER
Travel	6	49	CER
Trust	6	121	CK
Values	1	5	CK
Voluntary	3	12	CER
Will	6	56	C A/I

### Appendix 3: Categories Informing Stages of Contemplation

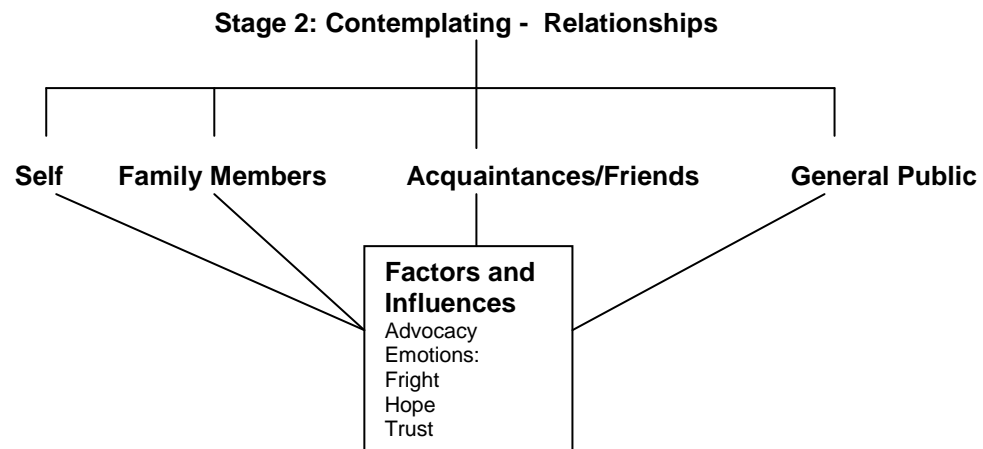
Stage	Categories
Contemplating – Knowledge	Awareness
	Experience
	Knowledge
Contemplating – Relationships	Self
	Family Members
	Friends/Acquaintances
	General Public
Contemplating – Actions/Inactions	Communication
	Actions/Inactions
	Suggestions for Improving Uptake



## Appendix 4: Basic Social Psychological Process – Contemplation

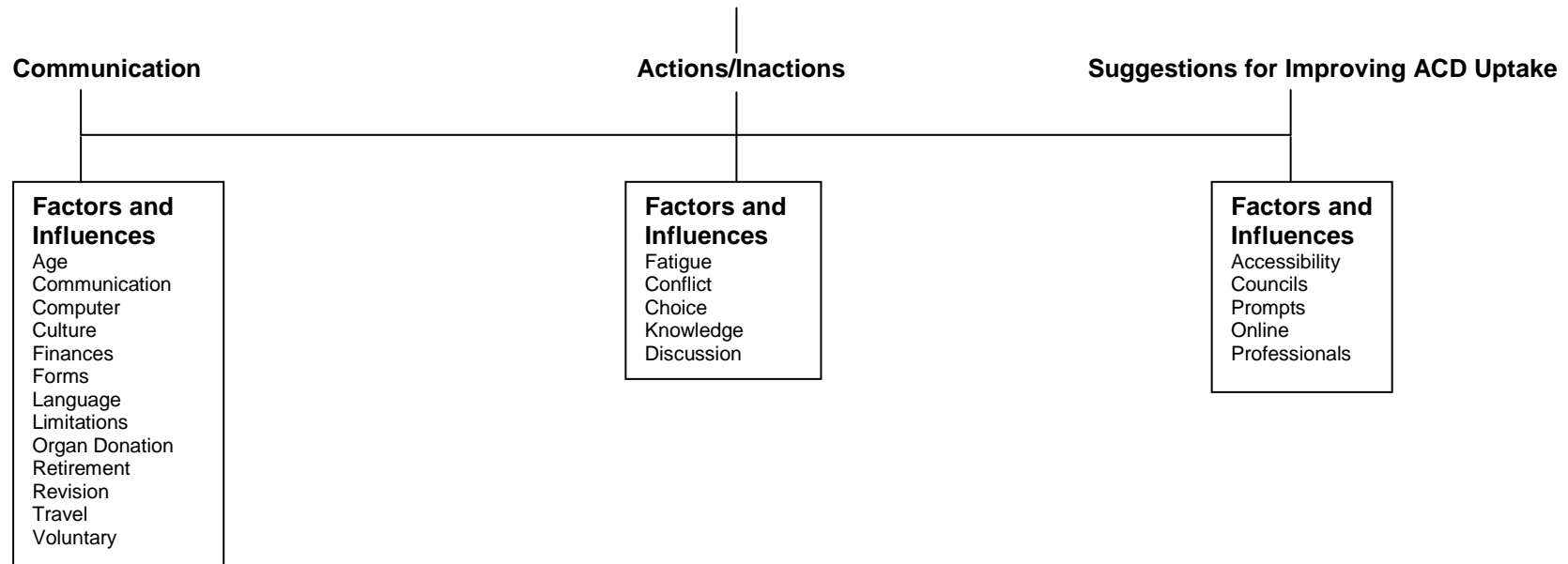


These factors and influences help define the knowledge SA Boomers incorporate into ACD decision-making. This knowledge is then considered in the context of the relationships they hold with others as defined in the next stage of contemplation, Contemplating – Relationships.



When awareness, experience and knowledge of the consequences of lack of or availability of ACDs are considered in context with relationships, then SDM nomination and ACD creation is contemplated. Successful creation of ACDs, however, depends on additional elements occurring as identified in the following stage of contemplation, Contemplating Actions/Inactions:

### Stage 3: Contemplating – Actions/Inactions



So, in the end, creation of ACDs occurs for the following reasons:

- Reduce potential future conflict
- Gain control over what happens to future self based on knowledge of what has happened to others
- Take responsibility for others either in generations above or below
- Reduce risk
- Provide and Seek Support

Whilst rejection of creation of an ACD occurs because:

- It is not seen to be the right time
- A SDM is either unavailable or can't be determined
- The forms are not readily accessible or too complicated
- The forms are available but it is difficult to actually write what a person wants to happen to them

## Appendix 5: Theoretical Concepts/Themes Describing the Three Stages of Contemplation

<b>Categories for Stage 1: Contemplating - Knowledge</b>	<b>Theoretical Themes for Stage 1</b>
Awareness	Behaviour and Consequences
Experience	The Ageing Process
Knowledge	Meeting the Needs of Others as an HCP or SDM
	Experiencing the Healthcare System
	Being the Communicator
	Understanding Illness
	Avoiding Residential Aged Care Facilities
	Saying 'No More'
	Cultural Influences on ACD Decision-making
	Funeral Planning
	Talking about the Same Thing
	Filling in the Forms
<b>Categories for Stage 2: Contemplating – Relationships</b>	<b>Theoretical Themes for Stage 2</b>
Self	Having the Discussion
Family Members	The Values of Others
Friends/Acquaintances	Advocating for Others
General Public	Finding a SDM
	Who Will Decide for Me?
	Managing Conflict
	Supporting the SDM
	Seeking Sibling Support
	Considering Children
	Faith, Hope and Trust
<b>Categories for Stage 3: Contemplating Actions/Inactions</b>	<b>Theoretical Themes for Stage 3</b>
Communication	I Know I Should, but I Haven't
Actions/Inactions	Deciding Not to Act
Suggestions for Improving ACD Uptake	Socialisation of Dying
	Making ACDs More User Friendly and Timely
	Speaking to a Professional

## Appendix 6: Example of Memo

9 October Wed, 8 Oct 2008

Conducted 5th interview yesterday but couldn't write about here until this morning as I had to teach straight after the interview. Bit of a shame that as this interviewee was slow to start and might have provided a bit more if we had been able to go a bit longer. She was a good interviewee, Ms Donella, as she had most of her experience in **country hospitals in residential aged care** acting as the CEO of the home and not in a direct nursing role. Interestingly, she was very unclear about what an advance directive actually was and her only known direct experience was being named a medical agent for a patient in her aged care home who was moved to another home. We discussed the conflict of interest in this relationship but most importantly was that she said most of the people who came into the home had already had their ad's completed before coming to the home. I asked why this might have been and she suspected that they may have been wealthy farmers and it may have been part of the estate planning. This makes me think I really need to try and get some interviews with lay people, not healthcare professionals now. I have written to Dr Frances Coombe to ask if she would put my flier in the SAVES next newsletter as there may be some younger members of this organisation who might be willing to participate in the interview process. Basically, Ms Donella said that age and her father's death five years ago were what keep prompting her to do her directives but she still hasn't done them because they aren't "in her face". In this interview, I had to actually explain the different directives and how they work which is something I hesitate to do during interviews, but I needed to do this to clarify her knowledge of them which was actually quite confused. When we discussed the confusion, she said the terms are bandied about and she thought an advance directive was one all-encompassing piece of paper that determined what was to be done at all levels, financial, health, etc. I explained that advance directive was a generic term to describe the instruments themselves and each instrument had different functions and requirements. We talked about who she would nominate and she said she has discussed her wishes very emphatically with her daughters and knows that one daughter would do as she wants but probably not the other daughter. I also asked her why she chose to participate as she responded to my advertisement in one of the local hospitals and she said it was because she is currently doing a grad dip or cert (we didn't discuss) and had to do research (which she didn't enjoy) but thought she would do the right thing and help someone else with their research as her daughter was currently a 3rd year and having to do a Lit Rev and struggling. There were parts of the tape that she didn't wish to be transcribed and that was fine but they didn't really have much to do with AD's and were more about her experiences with the Guardianship Board. Really interesting interview but took a bit of time to draw out the information and I felt myself leading the interviewee too many times. However, my leading clarified what she said or felt and in some instances actually acted for her to correct me, which was what I wanted. I will need to make sure that I provide up to two hours time per interview from now on to allow for people with slower response rates to questions. Ms Donella said she enjoyed the experience and was surprised to see that I could ask questions without the need to write them down and they seemed to just flow from the conversation. That was good feedback on my interview technique. I later described the methodology for her and that my list of prompt questions was gradually getting longer the more interviews that I was doing.

## Appendix 7: Memo after Coding

Post-coding Mr Xavier – 25 October 2010

The overall themes coming out of this interview are centred around prompting and guidance in discussion of advance directives. Specifically, Mr Xavier found it difficult to have a discussion about ads with his partner who was from a different cultural background and may not understand or be willing to accede to his requests without support and discussion. Another example given was that of the situation that occurred with his mother who nominated her agents (including Mr Xavier) without prior discussion as to what she meant by “not being kept a vegetable” in a manner that Mr Xavier could identify with.

Mr Xavier also felt that the forms should be on-line for ease of use and flexibility in changing conditions of the ads as time moved forward and a person’s situation changed.

His experience with ads in his position as a mental health nurse provided background for his contemplation of his own ads but were not overly influential. It seemed more the experience of his father’s death and his mother’s subsequent ads have provoked consideration of his own ads without his having actually done them, yet. These experiences seem to have also made him consider how his partner would be able to handle things if she was required to do so.

Post-transcribing Ms Donella – 31 October 2010

Ms Donella does not have ads for herself but has been considering them since her father’s death and step-mother’s illness and subsequent death five years ago. This is what has made her contemplate doing ads though she has not done so, yet. She has discussed what she wants done with her daughters verbally and has identified that her younger daughter would be more pragmatic and able to carry out her wishes.

She has been a medical poa in the past in her position in a nursing home in a country town which overstepped the bounds of technically being able to act as an agent for someone under your care but this was rectified when the person she was acting for was moved to another facility. However, this experience did not provide her with in-depth knowledge of all advance directives and there was confusion throughout the interview as to which instruments there were and how/when they were to be applied so this interview served as an education session as well.

My having to educate participants that claimed they knew and understood ads in order to participate in the interviews is an interesting outcome of this project.

## **Appendix 8: Questions for Interviews**

### ***Questions for Interview on June 2008 with Mr Zed***

#### **Open-ended First Question**

- 1) What is your experience with advance directive?

#### **Prompt Questions**

- 2) Can you tell me about bit more about what influenced your decision-making?
- 3) Did you find the forms useful?
- 4) Are there other factors involved in your decision-making relating to your age or physical well-being?
- 5) Are there any other things you would like to say or discuss?

### ***Questions for Interview August 2008 with Ms Belinda***

Questions 1- 5 same as for Mr Zed, first interview

Additional prompt questions:

- 1) Have you been influenced by what has happened to family members or friends?
- 2) How have you experienced the use of these directives in your work?
- 3) Is the language that we use on the advance directives an influence in their completion?
- 4) Have you had any dealings with the Guardianship Board and, if so, have they been influential in your ad decision-making?
- 5) Have family relationships been an influence in your decision-making?
- 6) How do you think people feel about death and dying in our current society?
- 7) Have you noticed cultural influences playing a part in completion of advance directives?

### ***Questions for Interview August 2008 with Ms Carmen***

Questions 1-5 same as for Mr Zed, first interview

Questions 6-12 same as for Ms Belinda

### ***Questions for Interview September 2008 with Mr Xavier***

Questions 1-5 same as for Mr Zed, first interview

Questions 6-12 same as for Ms Belinda

Plus additional prompt question

- 1) Do you feel that the public at large is knowledgeable about advance directives?

### ***Questions for Interview October 2008 with Ms Donella***

Questions 1-5 same as for Mr Zed, first interview

Questions 6-13 same as for Mr Xavier

Plus 4 additional prompt questions

- 1) Have you had any difficulties in discussing your directives with family members and, if so, what have they been?
- 2) When or how do you think the information should be made available to the public?
- 3) Do you think an on-line version would be helpful?
- 4) Which third party would you feel comfortable with discussing advance directives and in what location or setting?

**Questions for Ms Ethel February 2009**

Questions 1-5 same as for Mr Zed, first interview

Questions 6-17 same as for Ms Donella

Plus 1 additional prompt question

- 1) Which agency should be made responsible for promoting this information?  
Do you think we should be promoting the use of these directives?

**Questions for Ms Francine February 2009**

Questions 1-5 same as for Mr Zed, first interview

Questions 6-17 same as for Ms Ethel

**Demographic Questions:**

- Name
- Year of birth
- Type of employment
- Gender
- Had they created an ACD
- Had they been nominated or acted as SDM for an ACD



## Appendix 9: Ethical Approval Letter

Social and Behavioural  
Research  
Ethics Committee  
Room 105, Registry  
Building  
GPO Box 2100  
Adelaide SA 5001  
Tel: 08 8201 5962  
Fax: 08 8201 2035



**SBRE 4036**  
30 November 2007  
Mrs Sandra Bradley



Dear Mrs Bradley

**Project 4036** The influences on advance directive decision-making in those born between the years 1945-1965

Further to my letter dated 16 November 2007, I am pleased to inform you that approval of the above project has been confirmed following receipt of the additional information you submitted on 24 November 2007.

Approval is valid for the period of time requested or three years, whichever is the least, and is given on the basis of information provided in the application, its attachments and the information subsequently provided.

In accordance with the undertaking you provided in the application, please inform the Social and

Behavioural Research Ethics Committee, giving reasons, if the research project is discontinued before the expected date of completion and report anything which might warrant review of ethical approval of the protocol. Such matters include:

- serious or unexpected adverse effects on participants;
- proposed changes in the protocol; and
- unforeseen events that might affect continued ethical acceptability of the project.

I draw to your attention the requirement of the National Statement on Ethical Conduct in Human Research that you submit an annual progress and/or final report to SBREC. If a report is not received beforehand, a reminder notice will be issued in twelve months' time. A copy of the report pro forma is available from the SBREC website <http://www.flinders.edu.au/research/info-for-researchers/ethics/committees/socialbehavioural>.

cfm.

Secretary

Social and Behavioural Research Ethics Committee

cc: Dr Sheryl Delacey, School of Nursing and Midwifery

Dr Steve Parker, Nursing & Midwifery

NB: If you are a scholarship holder and you receive funding for your research through the National Health &

Medical Research Council please forward a copy of this letter to the Scholarships Office, for forwarding to the NHMRC.

## **Appendix 10: Advertisement for Participant Recruitment**

Are you interested in participating in a research study on Advance Directives?

Advance Directives are legal instruments which determine what health and lifestyle decisions you would want for yourself if you suffered an illness or injury which made it difficult for you to make these decisions at that time. There are four Advance Directives currently in use in South Australia. They are:

- Enduring Power of Attorney
- Enduring Power of Guardianship
- Medical Power of Attorney
- Anticipatory Direction

If you have recently completed any of the above, have thought about completing one or have rejected the idea of completing one, I would be very interested in asking you about your experience with the process. The aim of the research is to understand what has influenced your decision to use/not use advance directive.

### **Eligibility Criteria:**

- You must be born between the years 1945-1965;
- You must understand what is meant by an advance directive and have either completed one, contemplated completing one or rejected their use;
- Fluent in English;
- You must be living in the community either in an independent unit, home or independently in a retirement village.

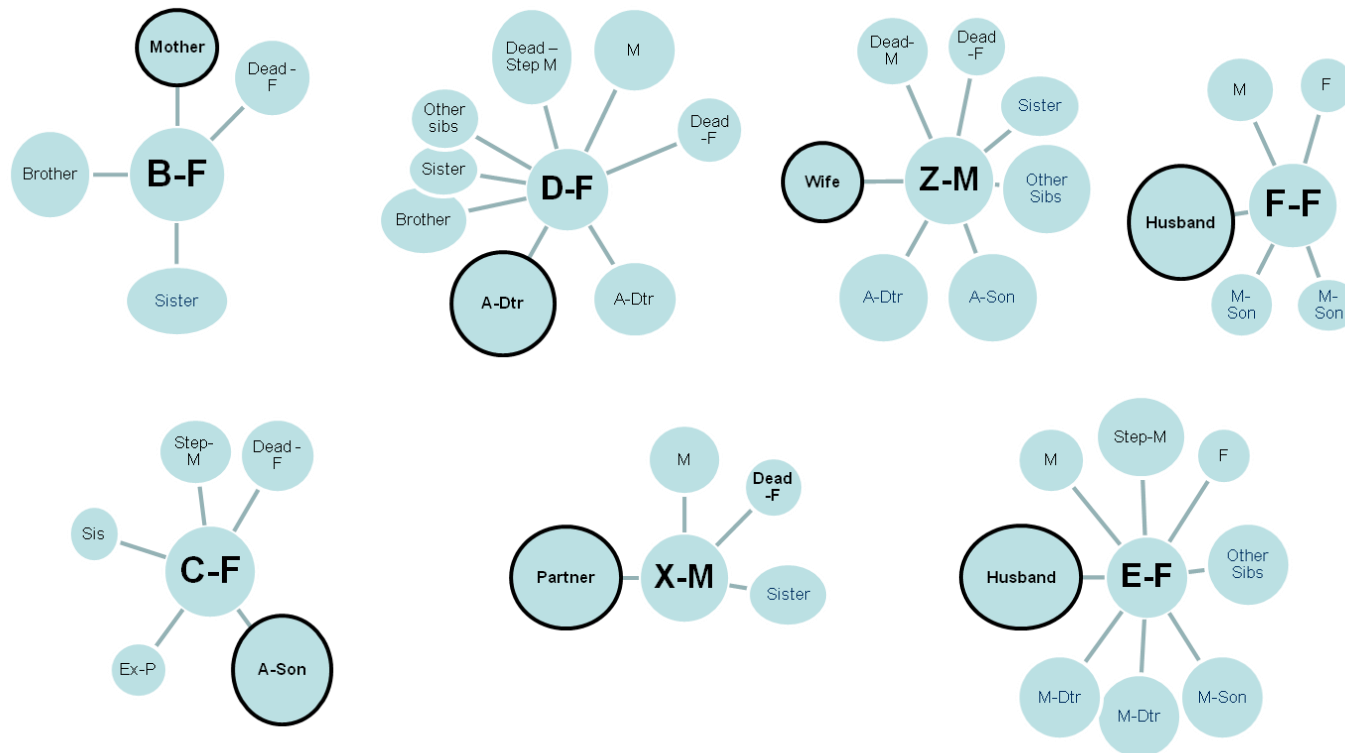
If you meet the eligibility criteria above, you will be asked to participate in an interview of approximately one hour, at a convenient location, to discuss your experience with the use of these directives.

If you would like to participate (and I hope you will!!!), please contact me on the number listed at the bottom of this advertisement.

*This research forms part of a Masters Thesis being conducted by the researcher through the Flinders University School of Nursing & Midwifery. Any questions or comments regarding this research should be directed to: Dr Sheryl DeLacey, Assoc Dean Higher Research Degree Students, 08-8201-5353*

## Appendix 11: Genogram of Participant Family Compositions

Centre Circle – first initial is first initial of participant, second initial denotes gender (M for male, F for female); Bold circle denotes chosen SDM



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