OLDER PEOPLE'S PERSPECTIVES ON ADVANCE CARE PLANNING: A QUALITATIVE AND QUANTITATIVE APPROACH

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Abstract

The use of life-prolonging medical technologies, such as cardiopulmonary resuscitation, have made it possible to prolong a person's life, even when death is inevitable and often with little regard for quality of life. Much of the decision-making regarding resuscitation takes place in the hospital setting or when the patient is terminally ill, where patient autonomy is compromised. The aim of this thesis was to address community dwelling older people's perspectives on resuscitation decision making and advance care planning. Using a social cognitive theoretical approach (specifically, the Theory of Planned Behaviour; TPB), the studies employed qualitative and quantitative methodologies to understand this under-researched area.

Study one a small, qualitative, pilot interview study (n=12) demonstrated the feasibility of conducting research on advance care planning among older people living in the community setting. The themes that emerged provided some support for using the TPB as the underlying theoretical framework and the findings were used to inform the next study.

Study 2 obtained descriptive data about older people's knowledge regarding advance care planning. In addition, this study assessed elements of the TPB and tested predictions from the TPB in a longitudinal design (n = 120, at time 1; n = 76 at time 2). The findings of this study identify constructs that are associated with older people's decision making on advance care planning and provide support that the TPB offers a conceptual framework to guide future investigations into advance care planning. Intentions and perceived behavioural control predicted intentions to discuss end-of-life issues with doctors (adjusted R-square = .38, p< .00) and sign living wills (adjusted R-square = .33, p< .00). Dying with dignity and attitude towards discussing end-of-life issues with the doctors predicted discussing end-of-life issues with doctors. Attitude towards end-of-life issues with the doctors predicted signing living wills. However, not all of the expected relations predicted by the TPB were supported, leaving a number of

questions for further study. To obtain a better understanding of some of the variables in the model, the next study used a qualitative approach.

Study 3, a focus group study (n = 48) was used to understand the attitudinal, normative and control beliefs of older people's views on resuscitation and advance care planning by investigating the meaning they ascribe to these concepts and to provide triangulation for the findings of study 2. Using interpretative phenomenological analysis (IPA), this study also shed light on the issues that older people contemplate prior to making decisions about resuscitation and why some older people think about making resuscitation decisions and advance care planning decisions, while others fail to think about these issues. The findings suggest that a pre-requisite to advance care planning was thinking about and accepting the inevitability of death. The qualitative findings from study 3 confirmed and strengthened the results of study 2. The qualitative findings suggested explanations for and contextualized how older people handle decision making in a realistic, dynamic and complex environment, taking into account the wider social context of resuscitation decision making and advance care planning. Finally, the findings of this study provided further support for older people's preference for discussing their resuscitation preference with their family members.

Study 4 addressed the role of family members in advance care planning. Older people's (n = 69) and their confidants' (n = 53) views on resuscitation and discussing life prolongation with family members were assessed using a structured interview. The questions addressed the areas of quality of life, burden, for the sake of the family, taking age into account and value for pain avoidance. These values that older people take into account when making choices about resuscitation for themselves were compared with the values that their confidants (or family members) take into account when making decisions on the choice of life prolongation on behalf of their older relatives. In addition, older people's and their confidant's values towards discussion issues of life prolongation with each other were compared. The findings suggested that older people were more likely to have negative attitudes towards resuscitation than their confidants (t = -2.30, df

=120, p =.02). Older people and their confidants used different values when assessing their attitudes towards CPR. The findings of this study suggest that discussions of life prolongation within the family setting are not routinely conducted. If family members are to be involved in resuscitation decision-making and their views are to reflect the interests of their relative, it is imperative that these discussions take place.

Overall, these findings contribute to the understanding of older people's perspectives on resuscitation and advance care planning. From the older person's perspective, the primary goal of advance care planning is more commonly preparing psychologically for death and dying. These studies suggest that the TPB was a good choice for explaining older people's views on resuscitation and advance care planning, particularly when additional variables were added to the model. The model acted as a framework to guide the design and interpretation of the results. Limitations of the studies, directions for future work and implications for practice and policy are discussed in the last chapter of this thesis.

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Chapter 1:

Introduction to the thesis: Aims and overview

As a nation we take great pride in the dramatic improvements in mortality trends during the course of the 20th century. Premature death – death before old age – has been greatly reduced and for the majority of the people born in the 20th century, death has been postponed. However, we have traded in a dying process that is 'tame' and recognizable and occurs at home, for a dying process that is often 'wild', unrecognizable, institutionalised and medicalised. Advances in medical technologies have made it possible to prolong a person's life, even when death is inevitable, often with little regard for quality of life. Contemporary death can involve making hard medical decisions for older people, their medical professionals and their family members. Medical and legal guidelines recommend that patients are involved in resuscitation decisions. However these difficult decisions are normally made in a hospital setting or when the patient is terminally ill, which compromises the patient's rights of autonomy and self-determination. Therefore, advance care planning (making the decision prior to serious illness or incapacitation) is recommended.

The broad aim of this research was to understand community dwelling older people's perspectives on initiating and holding discussions on resuscitation with their doctors and/or family members and/or drawing up living wills (advance care planning). The decision to perform these behaviours is guided by whether or not older people want resuscitation for themselves. Therefore, the thesis also addresses older people's conceptualisation of making decisions as to whether they prefer resuscitation for themselves. The Theory of Planned Behaviour will be used as a foundation of the emerging model (see Figure 6.1) to predict older people's intentions and performance of advance care planning. Furthermore, the thesis addresses and compares the older people's and their confidants' (family members) perspectives in making resuscitation decisions and advance care planning and the factors that influence these decisions for both the parties involved. Finally, the thesis explores various methodological issues. The empirical data collected through both qualitative and quantitative methods was evaluated and the issues of combining and using both these approaches were highlighted.

1.1 Summary of the chapters

Chapter 2 introduces the legal and medical aspects of Cardiopulmonary Resuscitation (CPR) and the "do-not-attempt to resuscitate" (DNAR) order. The chapter addresses the social and historical context of death and dying in contemporary Western society. The chapter concludes with a brief overview of advance care planning – discussing life prolongation with doctors and/or family members and/ or signing living wills.

Chapter 3 reviews previous studies of older people's views on resuscitation and advance care planning, including the factors that they take into account when making decision about resuscitation. The problems of patient involvement in resuscitation decision making is highlighted and the case for advance care planning is made. The second section of this chapter addressed the theoretical basis of the studies in this research. In this section, social cognitive models of health behaviours are reviewed with the purpose of identifying which theory will be most useful for research on older people's decision making about resuscitation. Several social-cognitive models are briefly described and rejected as candidates on the basis that they may not be applicable to the behaviours under consideration. The Theory of Planned Behaviour is presented in greater detail and its appropriateness for this research is discussed.

The researcher's epistemological position is introduced in chapter 4. A brief description of qualitative and quantitative methods and a discussion of their underlying epistemologies follows. The case for choosing both qualitative and quantitative methods is made. A detailed account of the research strategies adopted by the researcher is provided. Further, the criteria used for assessing good practice in qualitative research are discussed and a personal reflection on the motives for embarking on this topic is presented.

Chapter 5 reports the findings of Study 1. Study 1 is a small, qualitative, pilot interview study (n = 12) examined the feasibility of conducting research on advance care planning among older people living in the community setting, using content analysis. The study addressed the extent to which older people living in the community discuss life prolongation, the issues that were important to them and the different ways in which they make arrangements for their care in later life. This pilot study demonstrated the feasibility of conducting research on this topic with these older, community dwelling people. Moreover, the themes that emerged from the content analysis provided some support for using the Theory of Planned Behaviour as the underlying theoretical framework. Consequently, this theory was used to inform the next study.

Chapter 6 reports the findings of Study 2 which obtained descriptive data about older people's knowledge regarding advance care planning. The study also assessed elements of the TPB and tested predictions from the TPB in a longitudinal design. In addition to TPB constructs, other psychological predictors (as identified in the previous study and past literature) of whether older people discuss end-of-life issues with their doctors and/or signing living wills (or advance directives) were assessed. The longitudinal design involved a six month follow up. At time 1, predictors of older people's (n = 120) intentions to discuss end-of-life issues with their doctors and their intentions to sign a living will were explored. Six months later at time 2, (n = 76) their corresponding behaviour was assessed and predicted using time 1 variables. The findings of this study identify constructs that are important for older people when making decisions on advance care planning and provide support that the TPB offers a conceptual framework to guide research in future investigations of advance care planning. However, not all of the expected relations predicted by the TPB were supported, leaving a number of questions for further study. To obtain a better understanding of some of the variables in the model, the next study used a qualitative approach.

Chapter 7 reports the findings of Study 3, which was a qualitative study using focus groups. Participants were recruited from a range of social contexts with the aim of eliciting a variety of opinions. Eight focus groups (n = 48) were used to understand the attitudinal, normative and control beliefs of older people's views on resuscitation and advance care planning by investigating the meaning they ascribe to these concepts. In other words, the phenomenological validity of the TPB was explored taking into account historical, psychological, social and economic views on these issues. Using interpretative phenomenological analysis (IPA), this study also shed light on the issues that older people contemplate prior to making decisions about resuscitation and why some older people think about making resuscitation decisions and advance care planning decisions, while others fail to think about these issues.

The final study addressed an issue that emerged as important from the previous studies: the role of family members in advance care planning. Chapter 8 reports the findings of Study 4 where older people's (n = 69) and their confidants' (n = 53) views on resuscitation and discussing life prolongation with family members were assessed. A structured interview was developed in which the member of each pair of participants was interviewed separately. The questions addressed the areas of quality of life, burden, for the sake of the family, taking age into account and value for pain avoidance. These values that older people take into account when making choices about resuscitation for themselves were compared with the values that their confidants (or family members) take into account when making decisions on the choice of life prolongation on behalf of their older relatives. In addition, older people's and their confidant's values towards discussing issues of life prolongation with each other were compared.

Chapter 9, the General Discussion, summarises the findings of the four empirical studies and evaluates the extent to which the goals the research were achieved. The appropriateness of the TPB as the guiding theoretical model is considered. The limitations of the research and directions for future work are addressed. Finally, the chapter addresses implication for policy and practice.

Chapter 2:

Making the resuscitation decision: Legal, medical, social and historical background

In this chapter, Cardiopulmonary resuscitation (CPR) and the 'do-not-attempt to resuscitate' (DNAR) order are introduced, highlighting the legal and medical guidelines for the use and non use of resuscitation. Further, the social and historical context of death and dying in contemporary Western society is described. More individuals die in hospitals than at home, and these deaths are of older people who die from chronic, degenerative diseases. The development of medical technology enables healthcare providers to prolong the dying process and sometimes defer death without consideration for an individual's dignity and quality of life. The 'CPR for all' policy, which ensures anyone who suffers a cardiac arrest in a hospital is given CPR, and the DNAR order, which ensures that such an attempt to prolong life is not used, will be introduced. The collision of medical, legal and ethical issues that affect the experience of death and dying at the dawn of the 21st century will also be briefly described. The hospital death, advent of medical technology and the ethos of postponing death have lead to a death denying society. However, more recent developments and trends towards patient autonomy have encouraged individuals to discuss end-of-life issues. The resuscitation guidelines suggest medical paternalism; however patient autonomy and the right to self determination can be maintained by discussing resuscitation issues with doctors, family members or by signing an advance directive. The challenges of these will be discussed.

2.1 Life prolonging medical technologies

The term "life prolonging medical technologies" refers to treatments which have the potential to postpone the patient's death (BMA, 2001), and include CPR, chemotherapy and artificial nutrition and hydration. These are different from other basic care technologies such as pain relief and management of distressing symptoms, which are essential procedures to keep an individual comfortable at the end of life (BMA, 2001). There is also a difference between withdrawing and withholding treatment. Not administering CPR is withholding treatment. Withdrawing treatment is relevant to issues in euthanasia which is beyond the scope of this thesis. This thesis will only address life prolonging medical technologies (also known as life sustaining medical technologies), in particular CPR.

2.2 Cardiopulmonary resuscitation (CPR)

The pioneers of modern resuscitation in the late 1950's and 1960's were Drs. James Elam and Peter Safer, who discovered mouth-to-mouth ventilation and Drs. Kuwenhovern, Knickerocker and Jude who discovered the benefits of artificial compressions. In the 1960's, both these processes were combined to form CPR in the way it is practiced at present. CPR, described as 'closed chest massage' by Kouwenoven, Jude, Knickenbocker & Baltimore (1960) was originally intended to be administered to 'healthy patients' with reversible conditions, who experience a sudden and unexpected cardiac arrest. However, at present in the UK, guidelines indicate that the procedure of CPR should be applied to anyone being treated in hospital, regardless of their underlying medical condition. While successful CPR may restore vital signs, for those in the final stages of a terminal illness CPR prolongs the process of dying. It was only in the 1990's that the 'CPR for all' policy started to be practised in hospital in Western society.

CPR is emergency life support given to a person whose heart (cardio) and breathing (pulmonary) have stopped. The Oxford Concise Medical Dictionary (1998) defines it as the restoration of a person who appears to be dead. It depends on the revival of cardiac and respiratory function. CPR involves a combination of mouth-to-mouth rescue breathing (or other artificial ventilation techniques), chest compressions by repeatedly pushing down the chest firmly, using electric shocks to restart the heart and inflating the lungs through a mask over the mouth and nose or a tube inserted into the windpipe. In some cases this can restart the heart and breathing. A person's heart or breathing can stop as a result of a cardiac arrest (or a heart attack), drowning, electric shock or other injuries. During a cardiac arrest the organs do not receive a supply of oxygen-rich blood and so can begin to die. CPR circulates sufficient blood to lengthen the time before organ damage occurs. CPR comprises the elements of an initial assessment, airway maintenance, rescue breathing, and chest compression. These basic rescue skills are referred to as the ABC of resuscitation: Airways, Breathing and Circulation.

CPR includes both Basic Life Support (BLS) and Advanced Life Support (ALS). BLS, otherwise referred to as 'mouth to mouth' respiration or the 'kiss of life', implies that no equipment is employed. The purpose of BLS is to maintain adequate ventilation and circulation until the means can be obtained to reverse the underlying cause of the arrest. It is therefore a 'holding operation', although on occasions, particularly when the primary pathology is respiratory failure, it may itself reverse the cause and allow full recovery (Resuscitation Council, 2000). ALS involves a resuscitation attempt in a hospital setting where equipment such as defibrillators are used. During a heart attack, the electric activities of the heart can become chaotic rather than rhythmic. The heart, instead of pumping, contracts to produce ventricular fibrillation. Defibrillators treat ventricular fibrillation by giving the heart an electric shock intended to stop the abnormal electric activities and restart the normal rhythmic heartbeat. This thesis will only consider CPR in a hospital setting.

2.3 Efficacy of CPR: survival from a resuscitation attempt

CPR is able to retrieve the dying process and restart the heart when a person has a serious injury or a heart attack, but in the case of serious illness and near the end of life, where dying is the natural and expected outcome, resuscitation is less likely to be effective (BMA, 2001). Whether CPR will be initiated and will be effective in reverting the dying process depends on why the heart and breathing stopped working, the patient's general health, the presence of illness and other medical conditions and how quickly the heart and breathing can be restarted. When CPR is used on patients who are already dying (such as those in the terminal stages of a chronic condition or advanced age), it prolongs the pain and suffering of the dying person.

Studies have consistently demonstrated that CPR has very low efficacy rate. A recent multi-center survey and two meta-analyses which amalgamated over 100 studies on survival have suggested that in-patient CPR has an average initial success rate of 38 % (Schneider, Nelson & Brown, 1993; Tunstall-Pedoe, 1992; Von Guten, 1991). About 25 % of these initial survivors die before being discharged; thus, only 15 % of all patients who receive CPR in hospitals are discharged. However, the actual survival is much lower, as the figure does not take into account the patients who were considered poor candidates of CPR and on whom resuscitation was not initiated.

In reality, the proportion of people in hospitals who suffer cardiac arrests and who are successfully resuscitated is quite small. Medical teams view a "successful" resuscitation attempt as getting the pulse back (40-50 % success is typical), whilst actual survival rates (i.e. discharge from hospitals), viewed as "successes" by patients and their families, is much smaller. For example, Ebell, Becker, Barry & Hagen (1998) performed a meta-analysis of arrests in all hospitalised patients. They found that immediate survival after in-hospital CPR was 40.7 % and the rate of discharge was 13.4 %. Resuscitation Council (2002) suggests that only four out of ten patients will get their breath and heart beat back, after a resuscitation attempt. These clinical outcome measures of CPR can be quite misleading as less that one in five survive to be discharged from hospital (Resuscitation Council, 2002, CancerBacup, 2003). In older people or those with a chronic condition (including advanced cancer), only one out of every twenty patient survive to be discharged from hospital (CancerBacup, 2003). After a successful resuscitation attempt further treatment in warranted, such as coronary care and intensive care and most patients never recover completely to enjoy the same levels of physical and mental health they had before the resuscitation attempt. Almost all survivors have reduced functional abilities, neurological impairment, brain damage, social problems and a poor quality of life (Timmermans, 1999). In addition, an attempted resuscitation can leave the patient with bruises, fractured ribs and punctured lungs. Therefore it is imperative that a decision to initiate CPR is made after careful consideration because it may not result in recovery and/ or may leave the patient with multiple problems.

2.4 Do-Not-attempt to resuscitate (DNAR) order

The DNAR order ensures that universal indiscriminate resuscitation is not used to prolong life. The DNAR order, which applies solely to CPR and does not affect other areas of the patient's care, prevents patients from receiving cardiopulmonary resuscitation when the attempt to resuscitate is deemed to be futile.

National medical guidelines from the British Medical Association, Resuscitation Council (UK) and the Royal College of Nursing suggest that the overall responsibility for a DNAR rests with the consultant or general practitioner in charge of the patient's care (BMA, 2001). When the patient is competent their wishes must be taken into account when making the resuscitation decision, implying that this is a joint decision between the patient and the medical professional (BMA, 2001). The guidelines also state that when the patient is incompetent, the opinions of their relatives, or any previous wish expressed by the patient (such as an advance directive) should be taken into account when making resuscitation decisions. Often when these decisions are made, the patient is in hospital and may be incompetent, unconscious or incapacitated. If the patient cannot express their views, the views of family members or others close to the patient may be sought regarding what would be in the patient's best interest. Their role is to reflect the patient's views, not to take the decision on behalf of the patient. Therefore the patient should express their decision in advance, either by signing an advance directive or by discussing these issues with their doctors or family members.

An advance decision that CPR will not be attempted should be made only after appropriate consideration of all relevant aspects of the patient's condition including the likely clinical outcome, the likelihood of successful restarting the patient's heart and breathing, and the overall benefit achieved from a successful resuscitation; the patient's known or ascertainable wishes; the patient's right to life and the right to be free from degrading treatment (BMA, 2001). In addition, Article 3 of the Human Rights Act (1998) specifies that 'no one shall be subjected to torture, inhuman or degrading treatment or punishment' (Committee on Medical Ethics, BMA, 2000). The Act, incorporated into UK law, that came into force on 2 October, 2000, stresses that issues such as human dignity, communication, consultation and best interest are central to good clinical practice (Committee on Medical Ethics, BMA, 2000). The guiding principle reflected in any resuscitation decision is that individual's have a right to life, to be free from inhuman and degrading treatment, to respect for privacy and family life, to freedom of expression, which includes the right to hold opinions and to receive information, and to be free from discriminatory practice in respect of these rights (BMA, 2001). The spirit of the Act aimed to promote human dignity and transparent decision making, and is reflected in the national guidelines on resuscitation.

The BMA guidelines suggest that medical paternalism is favoured over patient's autonomy. Firstly, paternalism is revealed by suggesting that professionals have superior knowledge of the patient's condition including the likely outcome of resuscitation. Doctors often fail to inform patients about their underlying conditions and prognosis, which makes it difficult for patients to actively participate in decision making processes at the end of life. Secondly, the clause that suggests that patients may not be competent to act autonomously in resuscitation decisions as a result of physical and mental disability encourages medical paternalism. Literature supports this view of paternalism in the decision making process by suggesting that resuscitation decisions can be harmful to patients if it spoils the enjoyment of their last few days (Williams, 1993) and promotes psychological damage (Schade & Muslin, 1989). Patient autonomy is also compromised because the resuscitation decision often takes place only in later stages of a patient's illness and during hospitalisation where they may be incapacitated, unconscious or mentally incapable to participate in the decision making process.

2.5 Age and resuscitation

This thesis will address older people's perspectives on resuscitation decision making. There are various reasons why a choice was made to study older people. Firstly, the proportion of older people in the population continues to increase, along with their life expectancy. It has been estimated that 16 % of the population is presently over 65 years old and this is predicted to rise to 20 % over the course of the next 30 years. Based on the 1994 National Population Projections it has been predicted that by the end of year 2040 the majority of the population will be over the age of 50 (Age Concern England, 1999). Along with increased life span attributed to the advances in medical technology and public health, older people have chronic conditions or disabilities, terminal illness, multiple pathologies, high incidence of secondary complications and often a low quality of life (Clive, 2000). In line with the ageing of the population, the pattern of diseases that people suffer and die from is also changing. Increasingly, more people die as a result of serious chronic disease and older people in particular are more likely to suffer from multiple organ failure towards the end-of-life (Davis & Higginson, 2004).

Secondly, it has been argued that perceptions of death and dying in old age are radically different from those of death at younger ages, as manifested in services to support people who are dying (Clark & Seymour, 1999). Howarth (1998, p.673) suggests that older people's death is seen as 'natural', relatively straightforward and 'on schedule'. Therefore, they are less likely to be approached by specialised palliative care, based on the assumption that that older people know how to die and this is a natural death. Palliative and terminal care tends to focus on particular terminal illness, where older people are less likely to be referred to specialised palliative care of hospice services (Addingon-Hall, Fakhoury & McCarty, 1998). A plausible explanation for this is that palliative care is more easily organised for people who have a terminal diagnosis and older people have complex co morbid health problems which are little understood (Lloyd, 2004).

Thirdly, there seems to be some confusion over whether age has been associated with survival from CPR. Bayer, Ang & Patmy (1985) noted that most studies have failed to confirm that age has an independent influence on the prognosis of survival after resuscitation. Age per se has been inconsistently associated with survival after CPR, however some research suggests that younger age predicts better survival rates after attempted resuscitation in hospital (Heller, Stelle, Disher, Alexander, Dobson, 1995). The inconsistencies in these findings are possibly attributable to the fact that most of the research involved ill older patients, who often have a terminal illness and/or multiple pathologies.

Fourthly, there is evidence to suggest that age bias and discrimination exists on the part of the providers in resuscitation decision making (Bowling, 1999). Ebrahim (2000) suggests that it is unfair to withhold resuscitation using age as a criterion and this was regarded as discrimination and ageism. At the turn of the century, there was much media attention on ageism in the resuscitation decision and concern that despite BMA recommendations clinicians failed to discuss life prolongation with their older patients and concerns that the DNAR order was written in older people's notes without their knowledge. This was brought to light in the Age Concern England report on ageism within the National Health Service (NHS) and their campaign to eradicate ageist practices in the resuscitation decision (Age Concern England, 2000). The National Service Framework (NSF) for Older People (Department of Health, 2001) addressing improvements in health and social care of older people recommended that age discrimination is rooted out (i.e. all older people should have fair access to services or treatment whatever their age and there should be person-centred care in the NHS and all older people should be treated as individuals with respect and dignity). Age-related rationing of CPR through the use of the DNAR has contributed to a perception among older people of lack of autonomy when facing the end of life.

Finally, there is evidence that suggests that older people themselves do not want aggressive treatment in the final stages of life (e.g. Hill, MacQuill, Forsyth & Heath, 1994; Schiff, Rajkumar & Bulpitt, 2000). One plausible reason for this is maybe because of their own view of their declining health and the foreseen decline in quality of life caused by age, losing significant loved ones and having lived their life span, they tend to prefer the non-use of life prolonging technologies.

2.6 Social factors affecting resuscitation decisions

2.6.1 Blurred definitions of death and dying

Multiple definitions of death exists in contemporary society, which makes the distinction between life and death more complex. These blurred definitions of death make it difficult to determine whether life prolonging medical technologies should be employed. Death is defined as the 'absence of vital functions and is diagnosed as a permanent cessation of the heartbeat' (Oxford Concise Medical Dictionary, 1998). However, the definition of physical death is not that straightforward and various definitions exist. Biological experts have regarded *clinical death* as the interval between the time that vital processes have ceased and the time when permanent, irreversible damage has occurred. *Brain death* is demonstrated by a flat-line electrocenphalogram (EEG) refers to the cessation of activity in the neural structures that support and guide life. *Social death* however occurs when individuals are treated like they were already dead, even though they are biologically and clinically still alive (Clark, 1993; Glaser & Strauss, 1968; Sudnow, 1967, Timmermans, 1999). Social death does not necessarily coincide with bodily death and this is the image of death most feared under the high technological medical care. It is feared that when individuals are considered 'socially dead' (such as in the case of the frail old and terminally ill), the DNAR will be placed on the patient's notes or medical care will be discontinued. The continuing development of biomedical technology, such as resuscitation, has lead to new ways of assessing the constructs of death and dying. New technologies can now prolong some life functions (such as restarting the heart) resulting in the distinction between death and dying being blurred and confused (Blank, 2001; Feifel, 1977) and hence there is also room for disagreement and confusion regarding 'how dead' a particular person may be at a given point in time (Kastenbaum, 2000).

In addition, diagnosing dying is often a complex process. In a hospital setting, where the culture is often focused on "cure", continuation of invasive procedures, investigations and treatment may be pursued at the expense of the comfort of the patient. There is often a reluctance to make a diagnosis of dying if any hope of improvement exists (Ellershaw & Ward, 2003).

2.6.2 Death-denying culture and taboos about discussing death and dying

There is a body of literature suggesting that, despite its universal inevitability, modern Western society denies death and there is a taboo on discussing issues of death and dying. (Section 2.6.3 below presents more recent developments indicating a weakening of this denial and taboo). A death-denying culture makes it difficult to hold discussions about resuscitation. There are various reasons for the denial of death and the taboo on discussions of death.

The denial and avoidance of death has been attributed to the eradication of communicable and contagious diseases which resulted in a decrease in morbidity and mortality (Clark, 1993; Feifel, 1977; Katz & Sidell, 1994, Seale, 2000). Death no longer occurs in the home but in a hospital, with over 70 % of deaths taking place in hospitals or nursing homes (e.g. Grade, Addington-Hall & Todd, 1998; Higginson, Astin & Dolan, 1998). Older people are less likely than younger people to die at home (Grade et al., 1998; Higginson et al., 1998). This has resulted in death becoming the province of the 'professionals' (e.g. the clergy, physicians). Individuals also live longer and 70-80 % persons in industrialised countries now face death later in life from chronic or degenerative diseases characterised by late onset and extended decline (Clark, 1993). Death from chronic illness involves problems such as chronic pain, fear, dependency, loss of self-esteem and progressive de-humanisation and, with the breakdown or fragmentation of family and kinship groups, the previously existing institutional support is not present to cushion the impact of death (Feifel, 1977). Further, death is seen as a destroyer of the vision of the developing world - the right to life, liberty and pursuit of happiness.

The attitude of Western society towards death is characterised by fear and shame (Aries, 1983). People who are dying provoke unease and embarrassment and therefore it is deemed appropriate that they are removed from the community to die in isolation. The isolated death is the characteristic of modern institutional death, which is described as being denied, lonely and dirty (Aries, 1977). The 'Victorian' model of death was a 'tame death' which has been replaced by a 'wild' contemporary death.

The isolation of death has been closely linked to the rise of medicine (Foucault, 1965). Much of the silence and fear surrounding issues of death have been attributed to the medicalisation of death (Timmermans, 1999, Smith, 2000) which has led to lack of familiarity with death and dying compared to previous generations (Davis & Higginson, 2004). The advent of modern medicine, with its emphasis on postponing death, has lead to modern society organising itself to avoid death by viewing death as medical failure rather than a part of life and embarking on an elusive search for the postponement of death. Therefore, the silence and denial towards death may have resulted in individuals not thinking about their mortality or preparing for their deaths by making their wishes about life prolongation known. Further, the loss of religious beliefs may have also taken away a language and framework within which people can talk easily about death (Davis & Higginson, 2004). Furthermore, the media presents the public with images of death of other people – often sudden, untimely and often the fault of someone else (Davis & Higginson, 2004). This image had lead people to believe that death is something that should be fought against and avoided at all costs.

Elisabeth Kubler-Ross (1969) suggests that it is difficult for the human psyche to accept death and hence death and dying should be treated as a taboo subject as they signal finality.

> 'In simple terms, in our conscious mind we can only be killed, it is inconceivable to die of a natural cause or of old age. Therefore, we

> associate it with a bad act, a frightening happening, something that in itself calls for retribution'.
>
> (Kubler-Ross, 1969:2)

Psychologists and sociologists have contributed to the understanding of personal perspectives on dying (e.g. Kubler-Ross, 1969, Glaser & Strauss, 1968). Individuals not only think about death at the time of dying, but most people at any time are not free from concern expressed as either a fear or denial towards death and dying (Kastenbaum, 2000). Freud's (1913-53) work on 'Thoughts on war and death' suggested that fear of death are hints of deeper instinctual conflicts and suggested that individuals should contemplate death in the midst of life and will live in a more responsible manner for doing so. Becker (1973) also suggested that today's society was marked by heavy repression of death-related anxiety and it was important to give death some thought. In the context of making plans for the end of life, this is particularly relevant because only when an individual contemplates death can they make adequate provision to ensure that their dying process is in accordance with their wishes.

It has been postulated that older people are more likely to contemplate death and dying because of the signs of physical ageing and personal loss in the form of loved one's dying. Kastenbaum (2000) suggests that people become more anxious with advanced age because of the decreased distance from death. Alternatively, older people may become less anxious about death because death does not threaten as many goals and aspirations in an older person compared to a younger person. There may even be developmental processes which assist individuals to 'come to terms' with their mortality.

2.6.3 Cultural developments: more willingness to discuss death and dying

> 'We believe it is time to break the taboo and to take back control of an area (death) which has been medicalised, professionalised, and sanitised to such an extent that it is alien to most people's daily lives'
>
> (Age Concern, 1999, p. 41)

Over the past 25 years, death and the care of people who are dying have increasingly become matters of public discussion, and hence death is no longer regarded as a totally taboo topic and there is more of a willingness to talk about death and dying (Clark, 1993; Seale & Cartwright, 1996). The modern hospice service with the foundation of the St. Christopher's Hospice in 1966 and the death with dignity movement in the 60's and 70's have broken the conspiracy of silence about death (Seale & Cartwright, 1996; Timmermans, 1999). Key elements of the hospice approach include openness about illness and death, avoidance of prolonging life at the expense of unnecessary suffering, the recognition that symptom relief, particularly pain, is of prime importance, and the appreciation that family should be involved in the care of the dying relatives (Saunders & Banes, 1983). Moreover, the professional view of open communication and disclosure in the medical setting has resulted in more discussion about death with patients (Seale & Cartwright, 1996; Seale, 1991). Awareness of dying enables life planning to proceed and offers the hope of some degree of control over the manner and timing of death. Furthermore, it is recognised that death can be a desirable outcome of terminal illness. The importance of the therapeutic value of talking about fears and values has been established (Seale & Cartwright, 1996). These changes in attitudes towards death and dying in the 90's have resulted in the 'Right to die' movement, manifested as controlling the dying process by withdrawal or withholding support or active assistance in death (Euthanasia and PAS) (Timmermans, 1999).

2.6.4 Quest for an appropriate or a 'good' death

Medical technology and its emphasis on prolonging and postponing death have lead society to question an appropriate death or a 'good death'. This is primarily due to the belief that a technological and medical death leaves the person suffering with little dignity or control, and hence is a 'bad death'. Feifel (1977) suggests that an appropriate death is the absence of suffering, preservation of important relationships, interval for anticipatory grief, relief of remaining conflicts, belief in timeliness and the exercise of feasible options and activities.

Along the same lines, thanathologist Weisman (1974) suggests that an appropriate death is characterised by people choosing for themselves a death that includes several facets including a relatively pain free death, suffering reduced and emotional and social impoverishment minimised. Further, Kubler Ross (1969) in her book on 'Death and Dying' alerted people to the predicament of contemporary dying and proposed the idealised Victorian deathbed scene as a model of meaningful dying. More recently, ethicist Callahan (1993) listed the following criteria for an ideal form of death: the 'peaceful death' is meaningful to the dying person, the person is treated with respect and dignity, the person is conscious till near the time of death, the death matters to others and the dying person is surrounded by friends and relatives.

The Age Concern 'Debate of the Age' publication (1999) described 12 principles of a 'good death'- to accept that death is coming and what can be expected, to be able to retain control of what happens, to be afforded dignity and privacy; to have control over pain relief and other symptom control; to have choice and control over where death occurs; to have access to information and expertise of whatever kind is necessary; to have access to desired spiritual or emotional support; to have access to hospice care; to have control over who else is present and shares the end; to be able to issue advance directives which ensure wishes are respected; to have time to say goodbye and control over the aspects of timing and to have time to say goodbye when it is time to go and not have life prolongation pointlessly. All these definitions of what characterises a good death take into account key principle of wishing to maintain control over the dying process by retaining the right to autonomy and self determination.

The comprehensive study of older Aberdonians by Williams (1990) remains the most influential examination of the attitudes towards death and dying of modern community dwelling British older people. This work identifies a number of contradictory patterns in attitudes towards dying and in what constitutes a good death. In particular, there was incompatibility between two broad ideals of dying well: going as quickly and unconsciously as possible and going only after an affectionate reunion with kin. Bad deaths were those where death became 'arrested' (e.g. being a vegetable) and when the person became a 'burden to others' (Williams, 1990, p.99). The Aberdeen study supports the view that older people do not wish to know about their impending deaths, but did not suggest that death was highly feared among this cohort. More recently, drawing from interviews with people over the age of 75, Howarth (1998) shows the diversity of attitudes towards a 'good death' and contests the assumption that old age is the right time to die. Thus, the limited literature directly reporting on the attitudes of older people towards death suggests heterogeneity and complexity of attitudes.

Nevertheless, there is an accepted quest among older people, their medical professionals, medical ethicists and the law for an appropriate and good death. This good death involves the patient taking control of their dying process by making their own decisions about life prolongation. However, the new era of death is characterised by ambivalent attitudes towards denial, fear and an acceptance of the inevitability of one's mortality. Despite the doctor having ultimate responsibility for the resuscitation decision and the guidelines reflecting medical paternalism, there are different ways in which a patient can ensure that the dying process is in accordance with their wishes. In this thesis, three ways for an older person to retain control over the dying process are advocated.

I. Discussing options and preference with their doctors.
II. Signing an advance directive or living will.
III. Discussing these issues with their family members who can act in their best interest when they are incapable of making their own decisions.

2.7 Discussing resuscitation with the doctor

Medical professionals and patients make the resuscitation decision in different ways. The doctor is best equipped to offer a physiological analysis of the underlying condition and the likelihood of the resuscitation attempt being effective. However, for patients the use or non use of resuscitation takes into account their own values, morals and beliefs about the benefits of life prolongation for themselves. Doctors assess the situation of futility quantitatively (probability of survival) while patients make these assessments qualitatively, assessing quality of life (Landi, 1996). In the case of incapacitation, the family is called upon to reflect the patient's 'best interest'. Hence, it is vital for the patient, the healthcare team and people close to them (family) to be involved in resuscitation decisions and a discussion to help all parties to understand why treatment is given and why, in some circumstances, it may be unable to provide any benefit.

Research has consistently demonstrated that discussions on DNAR are difficult for doctors, families and hospitalised patients. These decisions are complicated by the fact that at the time these decisions are made, many patients are too sick to express their own treatment wishes (Bedell, Pelle, Maher & Cleary, 1986), or incapacitated or unconscious at the time of hospitalisation, when these decisions are normally made. This is especially relevant for older patients. A detailed discussion on these issues will follow in Chapter 3.

Despite medical guidelines, discussions on resuscitation between doctors and their patients rarely take place. Reviews of the literature reveal that physicians treat patients without knowing their preferences and patients lack knowledge of end-of-life treatment options (Marik & Zaloga, 2001; Steinberg & Youngner, 1998).The SUPPORT study in the USA demonstrated that physicians attend to their patients without knowledge of their preferences with regard to end-of-life care issues and most patients suffer significant pain in the final days of their lives (Bedell et al. 1986; SUPPORT, 1995). The literature suggests that physicians do not initiate conversations about end-of-life care with their patients for a number of reasons. For example, Lofmark & Nilstun (1997) found that 84% of the doctors made a DNAR decision without the patient's consent, believing that patients do not want to discuss the DNAR order. Medical professionals fail to discuss the DNAR order because they do not want to cause emotional pain or be the bearer of bad news and doctors think that by discussing these issues it may endanger the patient's health and life. Studies by Johnson and Pfeifer (1995, 1998) suggest that physicians do not want to damage patients' hope and are uncomfortable with managing the dying patient. Their own fear of death prevents them facing the death of their patients and their fears that they are not providing the best of care makes them avoid discussion of death and dying (Marik & Zaloga, 2001). They anticipate disagreement with the patient or family over futile treatment and fear malpractice (Casarett, Stocking & Siegler, 1999). Moreover, there is denial in the physician culture about the inevitability of death (Bedell & Delbanco, 1984; McCue, 1995; SUPPORT, 1995). In addition, research also suggests that physicians often resuscitate without discussion with the patient, with the belief that the patient would have wanted to be resuscitated or the belief that it would be 'safer to err on the side of caution' (Casarett et al. 1999). Further, due to little formal training provided to medical professionals when dealing with end of life care, they lack the appropriate communication skills to adequately discuss death with the patient and their family (Marik & Zaloga, 2001). These barriers make it difficult for medical professionals to make decisions and discuss resuscitation decisions with their patients.

Physicians face an ethical conflict when discussing the DNAR order with their patients. This conflict can be explained using the principles of autonomy and non-maleficence as value premises. The principle of autonomy implies that those who are capable of deliberation have a right to take part in decisions affecting them. Therefore clinicians have a duty to allow their patients to be involved in their own life prolonging choices. However, the respect they should have for personal autonomy conflicts with principle of non-maleficence, suggesting that harm should as far as possible be avoided.

The goal of medicine suggest that 'medical treatment should benefit the patient by restoring or maintaining the patient's health as far as possible, maximizing benefit and minimizing harm' (BMA, 2001, p.1). Therefore, if a particular treatment has no hope of providing a benefit to the patient and is likely to inflict pain, discomfort, suffering or loss of dignity, then it should be regarded as harmful, and not be offered to the patient. Therefore if medical professionals know that CPR will not have a positive outcome, then ethically the option should not be offered to the patient. Thus, medical professionals face a dilemma and often do not discuss DNAR status with their patients. The Hippocratic Oath of doing 'Do no harm' (primum non nocere) and where, possible, restoring or maximize health also create a dilemma of not doing harm by offering futile treatment to a patient in the form of resuscitation versus attempting to save a person's life by restoring life.

In addition, resuscitation decisions are often made at the end of life, defined as a period considered to begin when a person who has been diagnosed with a terminal illness that is incurable and irreversible has reached a point where appropriate parties such as the physician, the dying person or significant others have concluded that further treatment is futile and unwarranted (American Psychological Association, 2000). Patients are often not informed that they have a terminal illness and hence do not make their choices about life prolongation known. This usually occurs because of collusion, where there is a covert understanding between patients and their relatives that the news of a poor prognosis is kept from a patient. This often occurs when relatives argue that they are in a better position to judge and understand when the patient will not be able to handle the information. Hence it has been suggested that these discussions occur earlier, before the patient is hospitalised, so that the patient and the doctor can discuss these issues.

2.8 Advance directives

Contrasting with medical paternalism, where it is assumed that the 'doctor knows best' and hence is best equipped to make the resuscitation decision, personal autonomy suggest that the patient has the ability to decide whether or not to withhold life prolonging technologies. This is based on the premise that patients have control over their bodies and the right to self determination and therefore have the right to refuse treatment. Advance directives are a mechanism that ensures autonomy when the person is no longer able to direct the treatment.

In the UK, the terms "advance directives", "advance statements" and "living wills" are used interchangeably (Holt, 2002). The BMA, government and medical professionals tend to prefer the term 'advance directives', while the public is more familiar with the term 'living wills'. An advance directive gives patients the legal right to give or withhold consent to specific medical treatment prospectively and only comes into effect when an individual is incapable of making their own decisions. An advance directive is a statement made by a mentally competent person of 18 years or over, which defines in advance their refusal of medical treatment should he/she become mentally or physically incapable of making his/her wishes known. The advance directive stipulates which treatment he or she would like to receive or reject in a given set of circumstances. It provides some reassurance about the dying process being managed in accordance with their wishes, even if they will be too ill to communicate at that time.

The notion of living wills was proposed by lawyer Loius Kutner in 1969, responding to the fear that technology was driving doctors to impose life-sustaining treatment on patients who may not want it. The primary aim of living wills was to provide a legal defense against aggressive doctors. Advance Directives promote recognition of a patient's autonomy (Emmanuel, 2000; Molloy, 2000), giving the individual an opportunity to exercise a certain measure of control over life-sustaining care and treatment in the eventuality of becoming incompetent (Blondeau, Valoia, Keyserlingk, Hebert & Lavoie, 1998; Emmanuel, 2000; Fazel, Hope & Jacoby, 1999; American Psychological Association, 2000; Chiu & Li, 2000). This guards against futile treatment that could compromise the individual's dignity. More importantly, the process of signing a living will can stimulate and focus doctor-patient dialogue (Kendrick & Robinson, 2002). Advance directives can ease the emotional burden of the family, ensuring they do not have to be responsible for life and death decisions. Further, the process of signing advance directives can also educate individuals about their treatment choices and facilitate communication about issues relating to end of life care (Emmanuel, 2000). Molloy (2000) also suggest that advance directives help reduce health costs and alleviate anxiety among family members.

Advance directives have legal force in the United States and some provinces in Canada. Living wills evolved in the US with the first statute in the California Natural Death Act, 1976. Federal legislation however came into force with the Patient Self-Determination Act of 1990. In the UK, a valid advance directive is legally enforceable under common law[1]. This ensures that that legal action can follow against staff and medical faculty if the advance directives are knowingly ignored (BMA, 1999). The British Medical Association (BMA) first issued guidelines about advance statements in 1992. These were amended in 1995 when an advance statement was defined as a mechanism whereby competent people give instructions about what is to be done if they subsequently lose the capacity to decide or communicate (BMA, 1999). Since data collection for this thesis, the Houses of Parliament passed the Mental Capacity Bill, 2004 giving advance directives legal status according to statutory law.

2.8.1 Criteria for the enforcement of advance directives

Firstly, the person must be mentally able and over the age of 18 when he or she makes the advance directive. Secondly, the person must be fully informed about the nature and consequences of advance directives at the time he or she makes it. Thirdly, the advance directive applies to the medical situation the patient is currently in. Fourthly, the person must not be pressurized or influenced by anyone else when he or she made the decision. Moreover, the advance directive has not been changed by the person either verbally or in writing since it was drawn up. Finally, the advance directive only comes into force if the patient is incapacitated because they are unconscious or otherwise unfit.

2.8.2 Problems with advance directives in practice

Advance directives were developed in the US where the healthcare system is different from the UK. In the UK, until very recently, there has been no standard form or a legal framework for its use. Under the Mental Capacity Bill (House of Commons, 2004), advance directives have only just been recognised under statutory law.

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[1] A collection of judges' decisions about the law on subjects, where the parliament has not passed any statutes

However, there is little evidence in the UK of the effectiveness of advance directives and whether they achieve their theoretical aims. Medical professionals are unsure about the use and usefulness of advance directives, often associating them with euthanasia (Kendrick & Robinson, 2002). For individuals signing living wills, it is difficult to contemplate a situation that has not yet happened and often the actual scenario is quite different to the one envisaged by the patient. There is a presumption that an advance directive continues to represent the wishes of the individual unless it is revoked orally or in writing. Such a revocation may not be known to the healthcare team responsible for the patient. Moreover, there is no legal requirement for expert confirmation of mental capacity to execute an advance directive at the time it is made and there is no certainty that coercion has not been involved. The storage, revision and deliverance of an advance statement pose practical problems. An advance directive can act against the best interests if it is implemented in circumstances that were not precisely those which were intended. There is also the danger of a 'slippery slope', such as a situation where it can be used for economical purposes, such as saving scarce resources.

In the UK, the guidelines on advance directives drawn up by the NHS are left to individual hospital trusts to develop for policy & implementation (Diggory & Judd, 2000). A questionnaire survey conducted by Diggory & Judd (2000) found that only a quarter of all NHS trusts had developed or intended to develop policies on advance directives and less than 50 % of practitioners were aware that advance directives carry legal force (Bowker, Steward, Hayes & Gill, 1998). In the absence of national guidelines to support consistent end-of-life care, it is not surprising that 82 % of an elderly inpatient population in the UK had not heard about advance directives or living wills (Schiff et al., 2000). Despite the low levels of knowledge, 74 % expressed an interest in writing a living will (Schiff et al., 2000). Other studies have shown that while the public view it as good practice, only 13 % had a living will (Luttrell & Summerville, 1996). In comparison, research from the United States suggests that 83 % of the sample expressed knowledge of living wills and 29 % had completed a living will (High, 1993a). Further, the research by Palker & Carlson, 1995) indicates that only 52 % of participants document their advance directives.

2.9 Discussing end of life issues with family members

The resuscitation guidelines suggest that in the case of incompetence or incapacitation, the family will be consulted to act in the best interest of the patient. However no guidelines exist for which family members should be consulted and what happens about disagreement between family members. Other medical guidelines in the UK suggest that there is no legal right of proxy, however they are consulted in practice. In the US, the healthcare proxy or 'surrogate' has a legal right to interpret advance directives.

The arguments against the appointment of a healthcare proxy suggest that a significant number of people may not have someone to appoint or they may find it difficult to appoint such a person. This is especially relevant to older people who may not have immediate families who are alive or capable of being a surrogate decision maker. Further, at the time of decision making, proxies may not be emotionally capable of carrying out the patient's wishes. Emmanuel & Emmanuel (1993) suggested that for family members acting as surrogates making the decision itself can be considered a betrayal of the patient. There is also the concern that proxies (or family members) may not reflect that patient's best interest and evidence suggests that those close to family members err towards resuscitation (Seckler, Meier, Mulvihill & Paris, 1991).

2.10 Conclusion

The legal, medical, social and historical background for making resuscitation decisions have been introduced in this chapter. Despite medical guidelines propagating discussions on resuscitation and advance care planning, older people fail to make these decisions. A case for advance care planning in the community setting rather than in the hospital setting will be made in the next chapter, as a way of ensuring patient autonomy. The complexities of signing living wills, discussing end-of-life issues with the doctors and/ or family members will be further discussed. There are various reasons why older people fail to conduct advance care planning and how they make resuscitation decisions, which will be discussed in the following chapter.

Chapter 3:

The older person's perspective on resuscitation and advance care planning

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3.1 Introduction and Overview

The purpose of this chapter is to review previous studies of older people's views on resuscitation and advance care planning, including the factors that they take into account when making decision about resuscitation. Research conducted with either hospitalised or non-hospitalised patients, and healthy community living older people, will be reviewed.

Despite older people in hospitals wishing to participate in resuscitation decision making, they are rarely included. Issues of competency and problems with its assessment, medical professionals' discomfort in discussing these issues and resuscitation decision made in intensive care resulting in a decision being made in crisis mode will be discussed as reasons why patient participation in the DNAR decision is compromised. The timing of the resuscitation decision should therefore be considered, and decisions regarding CPR should be made in advance, prior to incapacitation, serious illness or advanced age. Advance care planning (ACP) involves discussing resuscitation issues with doctors, family members and/ or signing living wills. This also involves making decisions on whether the older person wished to have resuscitation conducted on them. ACP will give patients a chance to participate in the decision making process, in line with the patient's right to self-determination and personal autonomy. Researchers opposing advance care planning suggest that preferences about treatment are not stable over time. Evidence of stability of resuscitation preferences will be explored.

In practice, a discussion with doctors about resuscitation and signing a living will in the community setting rarely occurs. Other barriers to ACP in the resuscitation decision, such as inadequate knowledge and misconceptions regarding CPR will be discussed. Further older people's preferences towards CPR and the predictors of CPR preferences, namely socioeconomic factors, the presence of illness and the perception of functional status and quality of life will be considered.

Older people's views on who should be responsible and who should be involved in the resuscitation decisions show considerable variability. Some wanted to be the sole decision maker, while others wanted to defer the decision to medical professionals and/ or their family members. Others wanted a joint decision between themselves and their doctors and others wanted only the doctor and families to collaborate when making the decision. The factors that effect their decision on who should be involved in the decision making process will be highlighted. In addition, the scope for involving family in resuscitation decision will be explored. Finally, methodological difference in the studies will be discussed.

3.2 Little discussion about resuscitation in the hospital setting – discrimination between patient wishes and reality

BMA guidelines suggest that every competent patient should be involved in the resuscitation decision and doctors should routinely discuss these issues with patients before making DNAR decisions. A recent review by Frank, Heyland, Chen, Farquhar, Myers & Iwassa (2003) of 45 research articles relating to CPR information exchange, deliberation or decision making responsibility involving hospital patients over the age of 65 years found that the majority of patients (45 % -100 %) reported being comfortable and wished to be involved in the discussion and decision about resuscitation. Research suggests that in the hospital setting, despite a majority of patients wishing to be involved in the resuscitation decision, they are rarely consulted prior to the decision being made. For example in the US, despite the Self-Determination Act which indicates that all patients must be consulted about the DNAR order, discussions to obtain informed consent do not always take place (e.g. Bedell & Delbanco, 1984). In the UK, consultations about DNAR in the hospital setting rarely occur. In one study only 3 out of 627 patients who died without a resuscitation attempt had documented evidence that this had been discussed with the patient or the family (Keatinge, 1989).

3.2.1. Decision making capacity or competency

One of the major reasons why hospitalised patients are not included in the decision making process is due to the issue of competence. Patients in the hospital setting, close to the end of life may be incompetent, unconscious, have poor cognitive facilities and may be too ill to make a decision on life prolongation (e.g. Lo, 1991; Wenger, Kanouse, Collins, Liu, Schuster, Gifford, Bozzetter & Shapiro, 1995). Weiss & Hite (2000) in their systematic review of medical charts and death monitor sheets for hospital patients who had died in the US found that discussion about resuscitation with patients in the hospital did not often take place (only 11 %), as they are no longer mentally or physically competent to be able to participate. However research also suggests that despite 86 % of the patient group being competent to take part in the decision making process, only 19 % of patients with DNAR orders had been consulted about the order (Bedell & Delbanco, 1984). These findings suggest that competency may not be the only reason why patients are excluded from the decision making process.

Competent patients have the right to make decisions about their own health care, a right based on the ethical principle of autonomy and the legal doctrine of informed consent. Capacity or competence is the ability to understand the information needed to make treatment decisions and to appreciate the reasonable foreseeable consequences of the decision, which is specific to a particular situation and may vary over time. The capacity of the patient to make health decisions is assessed by clinicians in a health care setting. However there is no formalised and standardised way in which this assessment takes place. Doyal & Wilsher (1994) suggested that elderly patients must possess 5 basic requirements if they are said to be legally and morally competent to consent to non-treatment: (1) an understanding of simple explanations of their condition, prognosis, and proposed treatment (or lack of treatment); (2) their reasoning for non-use should be consistent with their personal beliefs; (3) they should choose to act on the basis of such reasoning; (4) they should communicate the substance of their choice and the reasons for their choice; and (5) they should understand the practical consequences of their choice. Further, Frank et al (2003) suggested that physicians should assess the decision making capacity of their patients by ensuring that patients understand information relevant for decision making by processing factual knowledge of CPR and the likelihood of success, and ensuring that patients appreciate the consequences of the decision or lack of a decision.

Patient participation in the resuscitation decision depends on the competency of the patient, which is the premise on which advance care planning is based. However, assessing capacity is problematic for a variety of reasons. Firstly, there is no reliable clinical measure of capacity to consent to treatment. Decision making capacity varies over time and determining the capacity to participate is complex and poses substantial challenges to medical professionals. When in doubt about the mental competence of a patient, physicians exclude patients from the decision making process. For example, Bradley, Walker, Blencher & Wetle (1997) found that a substantial number of residents from nursing homes (70 %) were inappropriately excluded from participating in discussions because of difficulties in determining decisional capacity to discuss future treatment choices. Staff were more likely to discuss advance directives with family members, often citing cognitive impairment as a reason for excluding older people from the decision making process.

Secondly, at the time of hospitalisation when the majority of DNAR decisions are made, the patient is too ill, unconscious, disoriented and mentally confused to be capacitated to make the decisions. Critical illness often diminishes the capacity of patients to make decisions. Steward, Wagg & Kinirons (1996) found that 32 % of elderly inpatients and 55 % of those with DNAR orders, had moderate confusion or else were too ill to complete a mental assessment and hence were unlikely to have been able to participate in clinical decisions. This leads to doctors making the decisions without consulting patients.

Thirdly, issues of competence are more relevant in the case of older hospitalised patients, and hence discussions are rarely initiated by the doctor. For older people, competence becomes an added problem due to deterioration of mental function related to age-related conditions such as Alzheimer's disease, delirium, dementia and depression. However, competency is specific and not global and hence care should be taken not to exclude patients on the grounds of incompetency because they have an illness, but rather a patient-centered approach to assessing competency relevant for advance care planning should be advocated.

Assessing and considering competency is of paramount importance in DNAR decision making, not only in the implementation of BMA guidelines, but also in the promotion of patient participation and autonomy. If incompetent patients are excluded from the decision making process, then ideally they should have been involved in making the decision in advance.

3.2.2. Medical professionals uncomfortable to discuss resuscitation with patients

Doctors fail to initiate conversations about the DNAR with their patients because they do not want to cause emotional pain or be the bearer of bad news. Doctors think that by discussing these issues it may endanger the patient's health and life and they do not want to damage patients' hopes. Research has also suggested that discussion about end-of-life care has an impact on completion of advance directives (e.g. Gordon & Shade, 1999). However, as suggested earlier (see chapter 2) medical professionals do not discuss treatment options with patients, and this perhaps could result in low completion of advance directives. Costello (2002) in his ethnographic study involving 3 wards in 2 hospitals in England found that doctors and nurses deviate from hospital policy by not involving patients in DNAR decisions. This was referred to as a protective strategy designed to alleviate distress for older patients.

Various authors have argued that involvement of the patient in the resuscitation decisions is unethical and illogical and therefore healthcare professionals should not discuss any form of ineffective treatment with a patient. Blackhall (1987) and Curtis, Park, Krone & Pearlman (2000) argue that personal autonomy and patient involvement regarding CPR intervention is irrelevant for many older people when CPR has no potential benefit and hence it is the responsibility of healthcare professionals. Thorns (2000, p.225) suggests that 'CPR is unique in clinical practice as it is the only situation which imposes an apparent duty on health professionals to discuss a futile treatment without request from the patient'. Therefore asking patients to make decisions on a medically futile treatment has been regarded as unethical.

An alternative view to that described above is that patients should be involved in the resuscitation decision because it is central to their autonomy and self-determination. Involving the doctor and the patient in a joint resuscitation decision, will allow medical professionals to offer expert medical advice and the patient to take into account their values while making the decision. In a hospital setting, this joint discussion, taking into account both expert medical and value factors, may not be feasible. Therefore, advance care planning, or making decision prior to incapacitation, serious illness or advanced age has been propagated. This may involve signing an advance directive, or discussing options with doctors prior to signing a living will. For example, Lo & Steinbrook (2004) suggests that patients should be encouraged to discuss advance directives with physicians and to complete them during an office visit. Such patient-physician visits could lead to more informed patient decisions.

3.2.3. Resuscitation decisions made in intensive care

Resuscitation decisions are normally made in the hospital setting, particularly in intensive care (see Seymour, 2000). Resuscitation decisions are made in this stage, as this is the time when cardiac arrest is most likely to occur and the time when doctors are clear about whether CPR is likely to be successful or not. At the time of hospitalisation, doctors have a clearer picture about the clinical outcome of CPR and hence decisions are made then. In the hospital setting, particularly when close to death or in the Intensive Care Unit (ICU), life and death decisions are made in crisis mode and the patient is likely to be incapable of participating (Danis, Southerland & Garrett,1991).

Therefore, it has been recommended that discussions on resuscitation occur earlier, when patients are able to participate and make informed choices (Quill, 2000).

Conversation about DNAR should take place before the patient is acutely and desperately ill. This would increase the likelihood that the values of patient autonomy and self determination are respected.

3.3 The case for advance care planning

As suggested in the previous section, patient participation in the resuscitation decision is compromised in the hospital setting. Discussion about resuscitation rarely occurs in the hospital setting, despite patients wanting to discuss these issues. However, as suggested issues of competence make patient participation difficult. Doctors are also apprehensive to discuss issues of life and death, such as resuscitation at a time of illness and closer to death. However, at the time of hospitalisation and closer to death, medical professionals are more able to predict the outcome of CPR, whether an attempted CPR is likely to result in success and failure. It seems that the timing of the resuscitation decision (in hospital) allows medical professionals to maintain dominance and patient autonomy and right to self determination is compromised. Therefore, these discussions should take place earlier – prior to hospitalisation, serious illness or advanced age. Johnston et al. (1995) found that 329 primary care patients' would prefer advance care planning and would prefer to discuss end-of-life issues relating to advance directives at an earlier age and earlier in the natural history of the disease. Majority of patients (91 %) agreed that advance directives should be discussed before patients are extremely ill and 84 % believed that discussions should occur when the patient is healthy.

Therefore, discussions with the doctor and family should take place in the community setting and older people should sign advance directives prior to being incapacitated or seriously ill are advocated. Discussion with doctors serve two purposes – allowing patients to understand and gain medical knowledge about the efficacy of CPR as well as allowing patients to inform their doctors about their preferences. Discussing issues with families allows the individual to take into account the family's views and also informs the family about the patient's wishes, so that the family can act in the patient's best interest when the patient is incapacitated. Further, these discussions with doctors and family members will aid patients in signing advance directives.

Some researchers have opposed advance care planning or discussions on resuscitation prior to hospitalisation on ethical grounds, arguing that individuals are likely to underestimate their desire to have medical intervention should they become ill and individuals in a 'hypothetical situation' are likely to use the denial mechanism, that involves the subconscious decision to die rather than suffer. Individuals confronted with death do not want to die and are prepared to put up with a certain amount of suffering in order to live longer (Ryan, 1996).

The basic assumption of using advance care planning is that people's preferences are stable over time and across changes in life condition. If treatment preference change substantially over time or with changes in an individual's life condition, then previously stated wishes stated before incapacitation may no longer reflect accurately the decisions that individuals would make for themselves when currently able. Several studies have examined the stability of life sustaining treatment preference over time (e.g. Carmel & Mutran, 1999a, Danis, Garrett, Harris & Patrick, 1994; Ditto, Dank, Houts, Coppola, Smucker & Jacobson, 2003; Emanuel, Emanuel, Stoeckle, Hummel & Barry, 1994). However, little attention is directed towards identifying psychological factors (see Carmel & Mutran, 1999a; Ditto et al, 2003). Overall the studies show that preferences are moderately stable over time. Consistent with past research, Ditto et al. (2003) in their study on 332 primary care older adults' preferences for 4 life sustaining treatments in 9 illness scenarios found that preferences were moderately stable over time (.76). However, Ditto et al. (2003, p. 612) maintains 'although a stability level of .76 in personality and attitudinal research might be taken as reflective of considerable stability over time, in the context of end-of-life decision making in which the stakes associated with misjudgment are higher, the fact that a quarter of all preference documented at a given time will misrepresent an individual's current wishes if consulted only 2 years later might be seen as producing unacceptable potential for medical error'. Despite these claims of a lack of stability of treatment preferences, suggesting a case against advance care planning, research suggests that stability is greatest for invasive treatments such as CPR (Ditto et al. 2003), refusal of treatment is more stable than preferences to receive treatment (Carmel & Mutran, 1999a; Danis et al., 1994; Ditto et al., 2003) and prior completion of an advance directive is related to preference stability (Danis et al., 1994; Ditto et al., 2003; Emmanuel et al., 1994; Weisman, Hass, Fowler, Gatsonis, Massagli, Seage & Clery, 1999). The treatment preferences of individuals who have invested effort to complete an advance directive reflect a high degree of thought and commitment (either prior to or because of completing an advance directive) and thus remain relatively resilient over time (Petty & Krosnick, 1995). Therefore, instead of discouraging individuals from advance care planning on the ground that they are moderately stable over time, individuals should be encouraged to sign advance directives.

3.4 Lack of advance care planning in non-hospitalised patients

Outside the hospital setting, older people think about resuscitation but rarely discuss the issue with their doctors. For example, Ebell, Smith, Seifert & Polinelli (1990) found that only 11 % of outpatients from a family practice had discussed DNAR with their physician, while 67 % had thought about the issue. Other studies have shown that while the public view it as good practice and show a willingness to use them (e.g. Kelner, 1993), only a small proportion had completed a living will (High, 1993; Luttrell & Summerville, 1996; Palker et al., 1995) A survey of 405 outpatients in the US revealed that 93 % desired an advance directive (Emanuel, Barry, Stoeckle, Ettelson & Emanuel, 1991), similar results (92.3 %) were obtained from 909 participants sample in Canada by Molloy, Guyatt & Alemayehu (1991). Recent studies reveal that only 15-25 % of the general public had completed living wills (Miles, Koepp & Webb, 1996). These findings suggest that despite older people supporting advance directive they rarely use them.

There are various other factors associated with the lack of patient involvement in the resuscitation decision and advance care planning. In the following sections these will be reviewed.

3.5 Inadequate knowledge about CPR

One of the prerequisites for patients' participation in the resuscitation decision is having sufficient information and knowledge about resuscitation. Research suggests that older people do not always have accurate knowledge about CPR and are therefore ill-equipped to make the decision. Studies conducted in the UK demonstrate that between 30 – 80 % of patients had heard about CPR (e.g. Gunasekera, Tiller, Clements & Bhattacharya, 1986; Liddle, Grilleard & Neil, 1994; Mead & Turnbull, 1995). Mead & Turnbull (1995) found in their questionnaire-based study that 80 % of patients due for discharge from a UK elderly care unit in an acute hospital had heard about CPR. Liddle and colleagues (1994) in their interview study found that only 30 % had accurate knowledge about CPR. Gunasekera, Tiller, Clements & Bhattacharya (1986) found that only 53 % of hospitalised patients in 3 geriatric acute wards had heard about CPR. The reason for the variability in evidence regarding older people's knowledge levels is because much of the research has focused on whether older people had heard of CPR (Gunasekera et al, 1986; Mead & Turnbull, 1995), while fewer studies have researched accurate knowledge about CPR (Liddle, Gilleard & Neil, 1994). To make a resuscitation decision, older people must understand what CPR entails and the implications of the treatment and non-treatment, prior to making a decision. Merely knowing what CPR does will not equip the individuals to make these complex decisions.

Particularly interesting when assessing knowledge rates about resuscitation, is the overestimation of survival rates of CPR and the false optimism about recovery. This has been attributed to acquiring information about resuscitation through the media. Resuscitation increasingly features in the lay media, particularly in television medical dramas. Television portrayals of CPR tends to show CPR as a successful and unrealistic procedure, where most patients survive with few adverse after effects. Older patients acquire their knowledge about CPR from the media, mainly through the television and therefore tend to over estimate survival rates of CPR (Bruce-Jones, Roberts, Bowker & Cooney, 1996; Mead & Turnbull, 1995). Patients who gave higher estimates of chances of survival were more likely to want CPR for themselves. For example, Frankl, Oye & Bellamy (1989) and Ebrahim (2000) in the US found that 90 % of patients preferred resuscitation, and treatment preferences were strongly influenced by the perceived outcome of CPR.

Various studies conducted on non-hospitalised patients also suggest that older people perceive CPR as a non-invasive intervention that either succeeds or fails, a perception based on information derived for the media (Carmel & Mutran, 1997; Carmel, 1999a, Murphy et al., 1994; Mead & Turnbull, 1995). For example, Carmel (1999b) in a large scale questionnaire study in Israel comparing the views towards life-sustaining treatments of physicians and older people living in the community and found that older people are more likely to favour resuscitation than their physicians. Carmel (1999b) attributed these pro-CPR views of community dwelling older people to the lack of public knowledge regarding the effectiveness of CPR.

Murphy, Burrows, Santilli, Kemp, Tener, Kreling & Teno (1994) in their study of 371 older patients found that after they had been informed of the probability of survival after CPR, most did not want to undergo the procedure. However, contradictory evidence suggest that even among patients who estimates their own chances of survival as approximately 25 % or less, more than half still wanted attempted resuscitation (Phillips, Wenger, Teno, Oye, Youngner, Califf, Layde, Conner, Lynn, 1996).

More recently, various UK researchers have proposed that television outcomes of CPR in the UK tend to more realistic, depicting more unsuccessful resuscitation attempts as compared to TV medical dramas in the USA (Gordon, Williamson & Lawler, 1998; Diem, Lantos & Tulsky, 1996). Therefore, it remains unclear whether TV portrayal of CPR affects older people's knowledge of success rates of resuscitation. There is a possibility that the advent of global television, where the public watches medical dramas not only made in the UK (such as Casualty), but also American-made dramas such as ER (Emergency

Room), may affect the over-optimistic view that the public has towards resuscitation.

Therefore, to sum up, older people have inadequate knowledge about resuscitation, with most having only heard about the procedure rather than having a realistic picture of the success rates of CPR. Knowledge about resuscitation is mainly acquired through the media, (particularly by the television), which lead to patients overestimating survival rates and thereby favouring resuscitation. Older people who were informed of the probability of survival were less likely to favour resuscitation. However, other researchers have suggested that despite low chances of survival, patients still wanted to undergo resuscitation.

Research suggests that not only is older people's knowledge regarding CPR unsatisfactory, but their knowledge about advance directives is also exceedingly low. For example, Schiff et al. (2000) in their study of 74 older inpatients in the UK found that 82 % had not heard of advance directives, while only 4 participants correctly defined them. Research in the US also suggests that patients misunderstood and did not have adequate knowledge about advance directives (e.g. Silverira, DiPieoro, Gerrity & Fendtner, 2000) and the lack of information and knowledge regarding advance directives is the main barrier to advance directives being used (e.g. Johnston et al., 1995).

It has been suggested that the misconceptions surrounding advance directives can be improved by increasing public knowledge of advance directives. Various education interventions (such as written material, videotapes) have been used to increase knowledge about advance directives. Patel, Sinuff & Cook (2004) in their systematic review of the effects of educational advance care planning on the completion of advance directives, directed to patients without terminal illness, found that advance directive completion rates documenting patient preferences for end-of-life care may be increased by simple patient directed educational interventions. Other research shows that moderate levels of interventions increased the use of advance directives (High, 1993; Brown, Beck, Boles & Barrett, 1999). Brown et al. (1999) compared the effectiveness of educational interventions involving written material vs. written material and videotape, and found that only one of the intervention vehicles is adequate to increase participation rates; the use of both led participants to re-evaluate the advantages of advance directives.

3.6 Preferences for CPR

There is a vast variety of preferences regarding CPR among older patients. Research on medical patients suggests that withholding CPR for seriously ill patients is not necessarily the norm and a sizeable proportion of chronically ill patients wanted to undergo resuscitation. For example, in a large study of chronically ill elderly adults in the US, the majority wanted to undergo CPR to be kept alive (Phillips et al., 1996), and few requested that a do-not-resuscitation (DNAR) order be entered into the charts (The SUPPORT Investigators, 1995).

Research suggests that a large proportion of inpatients (55 - 92 %) in studies from the UK wanted CPR (e.g. Bruce-Jones et al., 1996; Liddle et al., 1994, Mead & Turnbull, 1995, Sayers, Schofield, Aziz, 1997). Liddle et al. (1994) interviewed 100 older people due for discharge from an acute geriatric ward and found that 78 % expressed a wish to be resuscitated. Another study administered questionnaires to 214 older inpatients in two geriatric medical units at admission and at discharge and found that 60 % wanted CPR at admission and 53 % wanted CPR at discharge (Sayers et al., 1997). Watson, Wilkinson, & Sainsbury (1997) found that 38 % of older inpatients wanted resuscitation under any circumstances. However other studies suggest that older inpatients would rather forgo resuscitation in the final stages of their lives (Hill et al., 1994; Schiff et al., 2000). For example, Hill et al.(1994) found that 94 % of patients within 24 hours of admission wanted to decline resuscitation and 74 % would decline resuscitation before discharge from a general medical ward. Schiff et al. (2000) in their questionnaire study on medical inpatients also found that at the end of a terminal illness 90 % of older adults would decline resuscitation and preferred comfort care to active treatment.

These findings suggest that there is a wide variation in preferences towards resuscitation and older hospitalised patients may change their minds about their preferences at admission and at discharge, with some less likely to want resuscitation at the time of discharge (e.g. Hill et al., 1994) and others more likely to want resuscitation at the time of discharge (e.g. Sayers et al., 1997). The variations in patients' preferences for CPR have been attributed to a range of factors, which will be discussed in the following sections. These sections will also deal with the factors predicting advance care planning among older adults.

3.7 Predictors of preferences for resuscitation and advance directives

3.7.1 Socioeconomic factors

Sociodemographic characteristics, such as age, gender, marital status, race, education levels and socio-economic status (SES) have been used to predict older people's preferences for CPR. The SUPPORT Project using standardised interviews with 1,650 patients (mean age 62 years) from 5 geographically diverse academic acute-care medical centres in the US found that 28 % did not want to be resuscitated and demographic characteristics were associated with choices for no resuscitation. Factors associated with not wanting CPR included age (older people would rather forgo resuscitation) and gender (female were more likely to not want resuscitation). Gunasekera et al. (1986) in the UK found that out of 136 older patients from an acute ward, 42.5 % wanted resuscitation for themselves and refusal of CPR was associated with gender, with men more likely for prefer CPR. Studies in the US have found that older patients and woman are less likely to undergo CPR (e.g. Lo, Saika & Strull, 1985; Schonwetter, Walker, Kramer & Robinson, 1994).

Other studies have offered insights into why advanced age is associated with not wanting life prolongation. Rosenfeld, Wenger & Kagawa-Singer (2000) in their interview study in a senior & multilevel retirement community in the US found that advanced age is relevant for patients' treatment considerations. Older people were more likely to have experienced personal loss in old age and they considered death as appropriate at the end of a natural life span. Phillips & Woodward (1999) in the UK conducted a small qualitative study (focus groups) to investigate factors leading to resuscitation. The study suggests that age was not a deciding factor, but was referred to while making resuscitation decisions.

In addition to age and gender, other demographic characteristics are associated with preference for CPR. Bruce-Jones et al. (1996) found that favouring resuscitation was associated with marital status and functional dependence, with married and functionally independent patients favouring resuscitation. Miller, Jahnigen & Simbartl (1992) and Schonertter, Walker, Kramer & Robinson (1993) reported that those who most often desired CPR had low education levels. Schonwetter, Walker, Kramer & Robinson (1994) suggested a strong relationship between socioeconomic factors and preference: those who were non-Caucasian, less educated, and had less income desired more cardiopulmonary resuscitation. However, research also suggests that there is no relationship between demographic factors and treatment preferences (Emanuel et al., 1991). For example, Malloy et al. (1992) reported no significant difference in life-sustaining treatment decisions with respect to marital status and education levels.

In addition to predicting preferences for resuscitation, the demographic characteristics of patients have also been used to predict use or non-use of advance directives. Research has suggested that age and gender is associated with the completion of advance directives. The General Accounting Office (1995) in the US suggested that there is an age difference in the completion of advance directives with only 9 % of people under the age of 30 completing a directive compared to 35 % of persons over age 75. Charlson, Sax, MacKenzie (1986), Jonsson, McNamee & Campion (1988) and Lipton (1988) found that older people and woman were more likely to use advance directives.

Research also shows that educational levels are associated with knowledge and utilisation of advance directives (Ejaz, 2000; High, 1993b). High (1993b) found that 70 % of participants in the US with less than 12 years of education were familiar with advance directives, compared to 90 % of those with more than high-school education. Completion of a living will was associated with education:

21 % with those with less than high school education and 34 % with a higher education level had completed an advance directive (High, 1993b).

Ejaz (2000) found that religious affiliation was predictive of having an advance directives with Jewish participants being most likely to have completed advance directives (80 %), followed by Catholic participants (64 %), while Protestant participants were the least likely to have completed advance directives (19 %). Therefore it seems that variations in religious beliefs have an affect on whether advance directives have been completed. This is particularly relevant for older people, as individuals become more religious with age and even people who are not active in any religion revert to their religious roots when faced with death (Klessig, 1992). Older people have always been more religious than the young because of their concern with matters of mortality as death comes closer (Davis & Vincent, 1998).

Race and ethnicity have revealed an association with utilisation of advance directives, suggesting under utilization among ethnic minorities (Caralis, Davis, Wright, Marcial, 1993; Eleazer et al., 1996; High, 1993a; Morrison et al., 1998; Vaughn, Kiyasu & McComick, 2000). For example, High (1993a) found that 85 % of a white older sample were familiar with advance directives and 62 % had signed an advance directives, however, only 2 % of the black population had completed an advance directive. Caralis and colleagues (1993) found that Hispanics were less knowledgeable then African-Americans and Non-Hispanic whites about advance directives.

Even though not directly relevant to the present research, these studies of ethnic effects were reviewed as they provided reasons why advance directives were not utilised. These include: lower education levels and social inequalities associated with lack of familiarity of the DNR orders, cultural values of not talking about death as it brings bad omens, communication difficulties, mistrust of the healthcare system, fears of receiving inadequate medical treatment, and less likelihood of having an established doctor-patient relationship (see Eleazer et al., 1996; Morrison et al., 1998; Shepardson, Gordon, Ibrahim, Harper & Rosenthal, 1999).

Other research suggests that ethnic variations in utilization of advance directives is due to the family being central to the decision making process (Blackhall, Frank, Murphy, Michel, Palmer & Azen, 1999; Waters, 2000), hence older people from ethnic minorities prefer appointing a health care proxy than signing a living will (Morrison et al., 1998) and are willing to entrust the end-of-life decision making to the family (Vaughn et al., 2000). Vaughn and colleagues (2000) in their study on preferences among Asian nursing home residents found that the majority (72 %) of oriental older patients had no code or no advance directives. In explanation it has been suggested that social values, including harmony, respect for ancestors and responsibility dominant in the oriental culture discourages choosing DNAR, as this may be regarded as a display of utmost respect for elders. A DNR order is hence regarded as being unacceptable as it is viewed as giving up hope. A patient chooses CPR out of a feeling of responsibility to the younger generation to stay alive as long as possible (Vaughn et al., 2000). Therefore, advance care planning should take into account the patients' specific cultural views.

3.7.2 Perceptions and presence of illness and functional status

Although some studies suggest variations in resuscitation preferences based on demographic factors, it should be emphasised that preferences cannot be predicted by only patient demographic characteristics, but are also dependent on patients' perceptions of diagnosis and functional status. The presence of illness, especially the type of illness is an important consideration that is taken into account when making resuscitation decisions. For example, Watchter, Luce, Heast & Lo (1989) studying DNAR orders on patients with different diseases (AIDS, non-small cell lung cancer, cirrhosis and congestive heart failure) found that the rate of DNAR orders varied significantly by type of illness (ranging from 5 % to 52 %). Patients with congestive health failure and cirrhosis were more likely to prefer resuscitation than people with malignancies. The SUPPORT study suggested that not only did patients' illness but also the perception of prognosis affect treatment preferences. The study suggested that patients with heart failure and chronic liver disease were more likely to favour resuscitation and patients' perceptions of a worse diagnosis made them less likely to want resuscitation (Phillips et al., 1996).

In addition to the presence of illness, functional disability was associated with not wanting resuscitation. Phillips & Woodward (1999) in their focus group study on older people living in the community found that mental and physical dysfunction was an important deciding factor when making resuscitation decisions. Older patients would decline resuscitation more in the case of mental disability than physical disability. For example, Gunasekera et al. (1986) gave hospitalised inpatients hypothetical scenarios to make decisions regarding resuscitation. Their findings confirm that a larger majority of patients would forgo resuscitation in the case of mental dysfunction (76.2 %) than physical dysfunction (49.2 %). In particularly, the presence of Alzheimer's disease has been regarded as justification for the non-use of CPR (e.g. Resnick, Cowart & Kubrin, 1998) and most patients wished to continue treatment only as long as they were cognitively intact (Cohen-Mansfield, Droge & Billig, 1992).

The presence of illness and functional status has also been linked to advance directives. Patients with a diagnosis of cancer were more likely to have an advance directive, while patients suffering from dementia or cerebrovascular disease were unlikely to have signed a living will (Charlson, et al. 1986; Ghusn, Teasdale & Jordon, 1997; Jonsson et al., 1988). Castle (1998) in a large scale study of 5, 258 nursing home residents (mean age of 84 years), found that individuals who had increased physical impairment and congestive heart failure were more likely to have a DNAR order while increased age, cancer and terminal illness increased the likelihood of an advance directive.

3.7.3 Quality of life (QOL)

Medical professionals make decisions on the appropriateness about CPR by assessing current health status and likelihood that the procedure will result in success. Doctors tend to view the resuscitation decision as a medical assessment of health (Costello, 2002). In contrast, patients and the public make decisions on resuscitation, taking into account their own values, morals and beliefs about the benefits of life prolongation for themselves, often referring to the term 'quality of life'. For example, Carmel (1999b) found that elderly people were more likely to be concerned with quality of life when making decisions on life prolongation, while physicians were more likely to be influenced by the prognosis for length of life.

Patients would prolong their lives if they perceived that their quality of life is adequate, however if their quality of life was considered poor or inadequate they would rather forge life-prolonging medical technologies. Ebell et al. (1990) found that 93.9 % individuals preferred to preserve good QOL, even if it meant not living longer. Therefore, if a resuscitation attempt cannot restore a good quality of life, individuals would rather forgo treatment. In the UK, Phillips & Woodward (1999) found that older people tend to favour resuscitation when they had a desire to live, irrespective of the underlying condition and when their perceived quality of life was adequate.

However, patients' understanding of quality of life not only incorporated health assessment, but also included other considerations, including dying naturally and with no pain. For example, Singer, Martin & Kelner (1999) in their secondary data analysis of 3 studies on patients with dialysis, HIV and resident in long care facilities found that quality of life care involved dying naturally and avoiding inappropriate prolonging of dying. Patients were afraid of dying and of being kept alive when they were no longer able to enjoy their lives. While HIV patients in Aikman, Thiel, Martin & Singer's (1999) sample suggested that a good quality of life was associated with having no pain.

3.8 Responsibility for decision making

The BMA guidelines suggest that the doctor has ultimate responsibility for the resuscitation decision, but capacitated patients' views must be taken into account and the family's views reflecting the patients' best interest must be taken into account when the patient is incompetent. A review of older inpatients' views on resuscitation suggested that there is a large degree of variability in older patients' views on who should be responsible for the final decision regarding CPR. Frank et al.'s (2003) review indicates that between 19 - 92 % of patients wanted to be the sole decision maker, while a significant proportion (34 %- 59 %) wanted the decision to involve both themselves and medical professionals. Studies also suggest that older people would rather leave the decision to medical professionals and/ or their families. For example, Puchalski et al. (2000) conducted a secondary analysis of data from the Hospital Elderly Longitudinal Project (HELP) and the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments Study (SUPPORT). Their results suggest that the majority of seriously ill patients in the US would prefer to have their family and physician make resuscitation decisions for them (70.8 % of HELP participants and 78 % of SUPPORT participants), whereas a smaller proportion would rather make decisions themselves (29.2 % of HELP sample and 22 % of the SUPPORT sample.

Studies in the UK suggest similar trends and a large variation in views towards who older people wanted to be involved and responsible for the resuscitation decision. Bruce-Jones and colleagues (1996) found that 78 % of older people wanted participation, while 43 % wanted to be the sole decision maker. Older people who did not want resuscitation and had no spouse were likely to want to be the sole decision maker. Gunasekera et al. (1986) found that 32 % wanted to decide for themselves, while 57 % wanted the doctor to decide on resuscitation for them. Mead & Turnbull (1995) found that 64 % wanted their doctors to decide while, Liddle and colleagues found that 28 % wanted to be involved in the decision making process, 43 % wanted only the doctor to decide and 34 % wanted shared responsibility between doctors and themselves. Schiff et al (2000) found that older patients did not want their spouses (17 %) to be involved in the resuscitation decision, because they would be too emotional to make the decision. They would rather involve other relatives (63 %) or doctors (22 %) to make the resuscitation decision.

Closer inspection of these studies, suggest that some older adults feel that they themselves should be the sole decision maker of resuscitation, others suggest that they want only the doctor or the family to be responsible for the decisions. While some believe that it is a joint decision involving themselves and doctors, doctors and family members or family members and themselves. Older people wish to include physicians as they were regarded as an authority in the field of resuscitation based on their expertise in prognostication and treatment, while families are granted authority based on their concern for the patient's well being (Rosenfeld et al, 2000), while families needed to assume a degree of responsibility for representing the dying relative to ensure that the individual's right to self-determination was respected in the final stages of their lives (Seymour, Gott, Bellamy, Ahmedzai & Clark, 2004). Older people living in the community would want the opportunity to weigh the pros and cons of a particular course of treatment with their clinicians (Seymour et al., 2004). Johnston et al. (1995) found that 61 % of the adults believed that others should be included in advance care planning, most wanting their spouse or significant other and children to be included. Johnston and colleagues (1998) in their study on primary care patients and physicians found that patients were more likely than physicians to believe the physicians should provide a recommendation in addition to facts to help the patients make end of life decisions. Both agreed that it was the physician's responsibility to initiate discussions about advance directives.

In the following section, older people's desire to retain control over resuscitation decision, procrastination, denial and deferring the decisions and finally, issues of burden which seem paramount when making decisions about who should be involved in the decision making process and to what degree, will be discussed.

3.8.1 Maintaining sense of control

For individuals who sign advance directives, autonomy and the ability to enact self-control over one's life are identified as the underlying concept for making the decision (Collopy, 1990; Kelner & Bourgeault, 1993; Hoflin, 1988). For example, Eisemann & Richter (1999) in their study of public attitudes towards patient autonomy and advance directives found that the wish to maintain autonomy and self-determination was associated with support for advance directives. This desire for control or autonomy is related to fears concerning over-treatment. Eisemann & Richter (1999) found that those who expressed a fear for being treated aggressively were more likely to have an advance directive. Therefore, wishes to control one's destiny at the end of life and fears of being over-treated motivates an individual to sign a living will.

Other studies have suggested that not all older people wished to exercise control or autonomy in treatment decisions; some prefer to delegate the responsibilities to others. For example, Kelner (1995) exploring the views of elderly patients (n = 38) concerning control over the dying process found that a majority of participants (27) were 'activist', as they preferred to have a voice in decision making at the end of life. However, the 'delegates' (11) were more likely to delegate the decision to physicians, God or faith. The study suggested that desire for control was associated with socioeconomic characteristics - activists were more likely to be better educated, had held more professional and managerial jobs and tended more often to be middle class rather than lower class. They also had more knowledge about healthcare and were more likely to favour the withholding and withdrawal of treatment.

3.8.2 Procrastination, denial and deferring the decision

Despite a large number of people endorsing the benefits of advance directives, only a small percentage of them have actually made an advance directive (e.g. Palker et al., 1995; Johnston et al., 1995). The literature suggests that barriers towards signing advance directives include individual's tendencies towards denial and procrastination and the tendency to leave decisions to others (Palker et al., 1995). Patients often believe that clinicians or family are responsible for end-of-life decisions and hence do not make decisions about their care at the end of life. High's (1993a) interviews with 293 respondents aged 65 to 93 indicated that reasons for non completion include 'putting it off' and expecting others to take care of it when the time comes. Many of these older people preferred to defer the decision to family surrogates and avoid executing an advance directive.

3.8.3 Burden

Burden is a common theme for older people making decisions on CPR and those who are contemplating advance care planning. The concept of burden however means different things to different people. Firstly, signing an advance directive has been viewed as relieving family members from the burden of making decisions (Schiff et al., 2000; Seymour et al., 2004). For example, Schiff et al. (2000) found that older hospitalised patients were interested in signing a living will because they envisaged that this would relieve the burden of the decision on their family members. Secondly, older people often did not want to involve family members in the decision making process as this was envisaged as a burden on family. Aikman et al. (1999) in their study on proxy appointment among HIV patients suggested that patients were likely to exclude proxies in life-prolonging decisions to relieve feeling of guilt and not be a burden on caregivers.

Older people were also concerned about being a burden to their families in the later stages of life and this had an impact on preferences for end-of-life care. For example, Wilson (2000) in her qualitative investigation of 49 senior citizens preferences for end-of-life care in Canada found that older people were concerned about burdening their families, as family members may need to give up paid employment and their relationships may suffer. Some were concerned with the financial burden on care in the later stages of life, suggesting that burden on their families and society was an important consideration. However, others consider family caregiving a duty, an obligation and a responsibility (Wilson, 2000).

3.9 Surrogate or proxy decision making - involving the family member

Unlike the USA, where family members have the status of a healthcare proxy, the role of family members in end-of-life decision making in the UK is limited. The British Medical Association (1999) comments that if the patient cannot express their views, the views of family members or others must be sought regarding the patient's best interest. Their role is to reflect the patient's view and not to take the decision on behalf of the patient. Further, guidelines state that patients must be asked in advance who they want included or excluded in the decision making if they become incapacitated, thereby stressing the importance of communication about advance care planning within the family setting.

Older people wish to involve their families in the resuscitation decision making process. British studies have shown that 57- 77 % of patients would want their families involved in making decisions with, or for them, in conjunction with professionals (Morgan, et al., 1994; Liddle et al., 1994; Seymour et al., 2004). Family members are usually able to give valuable insights into incompetent patients' values and beliefs, which is information that is not easily available to medical professionals. This alternative of asking families about the patient's values and preferences for resuscitation is valuable to doctors, who often have to guess patients' wishes or make unjustified assumptions based on their own prejudice. For family members to appropriately act in the patient's best interest, they should made decisions in the same way, based on the same values as their incompetent relative. There have been very fewer studies comparing the views of older people and their surrogates (e.g. Landon, 2000; Sulmasy, Terry, Weisman, 1998). However, the findings of these studies are favorable suggesting that 66 % of nominated surrogates accurately predicted the views of the patient with regard to CPR (Sulmasy, Terry, Weisman, 1998). Alternatively, a discussion within the family setting prior to incapacitation would be appropriate. However, there is no documentation of older people's discussion with family members about resuscitation. Discussion with family members will ensure that the family member acts in the older incapacitated person's best interest, rather than making the decisions for them. Studies in the US have suggested that proxies also help in the interpretation of advance directives (Teno, Maruerite, Spernak & Lynn, 1998).

However, older people may find proxy appointment challenging. Gordin & Singer (1995) in their review on decisions and care in the end of life suggested that families move away from their ageing parents in Western society and their obligations of kinship to parents may conflict with their responsibilities to their own families and jobs. A significant number of older people may not have someone to appoint or they may find it difficult to appoint such a person. Spouses and partners may be deceased or may not be mentally competent to take on the role of decision maker. Children may have moved away from a parent, which makes proxy appointment difficult.

Further, older people may think that their family members would be too emotional in the situation to carry out the patients' wishes and would want to do everything to keep their dying family member alive. However, research has suggested that only a small proportion (8 %) of bereaved relatives believes that more should have been done to keep their loved ones alive (Hanson, Danis & Garrett, 1997). Teno et al. (1998) found that surrogates are often unavailable, ineffectual, or too overwhelmed with their own concerns to advocate effectively for the patient's best interest. It has been suggested that surrogate decisions are often discordant with the patient's own wishes, tainted with guilt, fear of losing loved ones, concern about possible accusations that they didn't show enough concern, or motivated by self gain (Hardwig, 1991; Seckler et al., 1991). Family members may interpret a decision to forgo resuscitation as a signal that the patient or providers have given up (Scanlon, 2003). Emmanuel & Emmanuel (1993) suggested that for family members acting at surrogates making the decision itself can be considered a betrayal to the patient. There is also the concern that proxies (or family members) may not reflect that patients' best interest and evidence suggest that those close to family members err towards resuscitation (Seckler et al., 1991).

3.10 Methodological issues

The inconclusive findings of these studies and interpretation of this body of research is hampered by a complicated web of methodological differences between the studies. The studies employed different samples, recruited from different medical settings (acute wards or geriatric units) and at different stages of hospitalisation (during discharge or during hospitalisation) where their views about resuscitation may be different. Most of the studies recruited participants at the time of discharge rather than at the time of hospitalisation when the decisions are normally made. Views of patients towards resuscitation may be different at the time of hospitalisation and during discharge.

Some of the research on resuscitation decision making employed a method of examining the charts of patients who died in hospital and working backwards through their hospital experience, by reviewing and analysing their medical charts and death monitor sheets. However, this method gives us little indication of the nature and depth of interaction between doctors, patients and their surrogates.

Another shortcoming of these studies is that the extent of illness or disabilities of the samples were unknown or different, with some living with chronic or progressive disease. Patients with different illness conditions may hold different views on the appropriateness of resuscitation. Further, some studies of advance care planning used hypothetical scenarios, asking patients to imagine that they had a medical situation such as a stroke, cancer or physical or mental dysfunction and then predict whether they would under those circumstances wish to be resuscitated. Participants' views in hypothetical situations and when faced with making decisions for themselves may be different.

In addition, research on non-hospitalised older people living in the community tends to be mainly US, Canadian and Israeli, with fewer studies in the UK (e.g. Seymour et al., 2004; Phillip & Woodward, 1999). National and hospital policies towards resuscitation are different in different countries and hence to apply the findings of research conducted in other countries may be inappropriate. The different historical, cultural, and legal factors operating in the UK make it difficult to generalize the results to the UK (see Seymour, 2000). In general the limited work in the UK has concentrated on medical and ethical studies, while social science research in the area has been limited. Therefore investigating the views of resuscitation and advance care planning in a sample of older people living in the community was considered appropriate.

3.11 Summary

The previous sections of this chapter reviewed the literature on older people's views on resuscitation and advance care planning and identified the main shortcomings in the literature. The conclusions of the literature review suggested that most of the research conducted on this issue has focused on hospitalised patients. Despite older people in hospitals wishing to participate in resuscitation decision making, they are rarely included. The results suggest that this could be due to issues of competency and problems with its assessment, medical professionals discomfort in discussing these issues and the resuscitation decision made in intensive care where patient participation in decision making is compromised. The timing of the resuscitation decision is therefore crucial when making decisions regarding CPR. Ideally, decisions should be made prior to incapacitation, serious illness or advanced age. The review of the literature suggested that there are wide variations in preferences towards resuscitation and a large degree of variability in older patients' views on who should be responsible for the final decision regarding resuscitation. Furthermore, the literature gives much importance to signing of living wills as a mode of advance care planning, while the literature on older people discussing CPR options with doctors and family members has been given less emphasis.

In the next section, we will identify a theory that can be used to explain older people's views on resuscitation and advance care planning.

3.12 Theoretical Models in Health Psychology Research

According to Ogden (2004, p.425) a good theory should 'consists of constructs that are sufficiently specific so as to generate hypotheses. Such hypotheses should be testable and a good theory should be able to be rejected'. Health psychology has relied extensively on social psychology for theoretical approaches (Rutter & Quine, 2002). In this section, social cognitive models of health behaviours are reviewed. The purpose of this section is to identify which psychological theory will be most useful for research on older people's decision making about resuscitation. More specifically, the health behaviours under consideration are those that are involved in advance care planning, which include holding discussions with doctors and/or family members about preferences for life prolongation, and/or the drawing up a living will or advance directive. Also, the decision to perform these behaviours is guided by whether or not older people want resuscitation for themselves. A theory is needed to help conceptualize the variables involved in the prediction of these behaviours. Understanding the determinants of intentions as well as actually engaging in the behaviours would be helpful for designing a framework for future intervention, so the theory should address both intentions and behaviours.

There are various characteristics of the behaviours in question which must be considered when deciding which theory to use. Firstly, advance care planning, discussing resuscitation with doctors, family members and signing a living will are complex behaviours which most individuals do not routinely consider. Performing these actions may not be a one-time decision, but rather may involve ongoing discussions with significant others, or the review of a living will when personal circumstances change.

Secondly, these behaviours are unfamiliar to people, and require them to think about frightening ideas, such as death and suffering, which they may prefer to deny. Further, making resuscitation decisions for oneself is difficult because an individual needs to weigh the cost and benefits for this procedure for themselves. They may not have adequate information about resuscitation and its efficacy and hence may need to consult medical professionals. In addition, their families will also be affected by their decision and may need to be informed about their wishes, so they can act in their best interest. The views about resuscitation of both doctors and family members will often be taken into account when making the decision. Therefore, both doctors' and family members' input and co-operation have an impact on a person's decision. In addition, a decision to prolong life or refuse treatment may be influenced by an individual's perception of death in society, particularly societal attitudes towards discussing these issues and the media portrayal of resuscitation. Therefore, social factors should be included as a possible determinant in a theory to predict behaviours involved in advance care planning.

Lastly, control or efficacy to perform the behaviour is of particular relevance to the study of advance care planning. Firstly, older people are not experts in the field of resuscitation; therefore they may feel a lack of control because of lack of knowledge. Secondly, older people may anticipate that they would not be compos mentis at the time of resuscitation and at the time the decision is made. The anticipated lack of control may motivate them to take control at the time when they are still able to make these decisions and conduct advance care planning.

Therefore, the theoretical approach to study advance care planning should have the following features. It should be primarily a model of rational decision making because the act of making a living will, or discussing these issues with a family member or doctor is a conscious and deliberate one. However, there is an emotional component, and this should be included in some way. For example, attitudes are derived from beliefs about the costs and benefits of outcomes and incorporate an evaluative (emotional) component. The model should include a component of perceived control over the behaviour. The broader social context for the decision should also be accommodated by the theory. The theory should be appropriate for complex behaviours that involve different components, and for which intentions may be an important intermediate step on the way to performance.

Based on the characteristics of the advance care planning, it was considered that social cognitive models would be most applicable in understanding and predicting the behaviours involved. Social cognition is concerned with how individuals make sense of social situations (Conner & Norman, 1996). Social cognition models seek to describe important cognitions or thought processes and the role they play in the regulation of behaviour. These models emphasis the rationality of human behaviour, where the predicted behaviour is the end product of a rational decision making process based on deliberative, systematic processing of the available information. These models assume that behaviour and decisions are based upon elaborate, but subjective cost-benefit analysis of the likely outcomes of different courses of action. Some of these models are based on the premise of subjective expected utility theory (SEU, Edwards, 1954), where it is assumed that individuals generally aim to maximise utility and so prefer behaviours which are associated with the highest expected utility.

A considerable proportion of health behaviour research within health psychology has been influenced to a great extent by the social cognition approach (Clark, 1994; Fiske & Taylor, 1991; Martin & Clark, 1990). Social cognition considers cognitions to be important factors determining behaviour. In particular, beliefs about the attributes of the behaviour as well as about the expected outcomes of the behaviour are considered to be important in understanding why a person will perform the behaviour in question. Social cognitions are considered important in understanding health behaviours as they are relatively stable characteristics that are used to form behaviour. Moreover, as they differ between people of different backgrounds, it is thought that they mediate the impact of intrinsic factors (e.g. sociodemographic variables, social support, personality, cognitions and personality), as well as of extrinsic factors (e.g. taxation, law, media and illegalization, external to the individual). Finally, members of the same social group usually share the same social cognitions, indicating that social cognitions are socially acquired and are open to change.

According to Clark (1994), social cognition and health psychology share three common characteristics. Firstly, both fields focus on the internal psychological processes of the individual, perceived as constructing their own perceptions of his/her social environment in order to operate and act within it. Perceptual, interpretational, inferential, memorial, judgmental and decision making processes play important roles within the theoretical frameworks of both fields of work. Secondly, both areas favour the development of theories that detail these processes. Finally, health psychology and social cognition share a common pursuit in understanding and explaining the relationships among affect, cognition and behaviour. Therefore it was considered appropriate to use a social cognitive model in explaining older people's views on resuscitation and advance care planning.

Conner & Norman suggest there are two broad types of social cognition models. The first, which they label as attribution models, are concerned with individuals' causal explanations of health-related events. As they note, the focus of much research within this tradition is upon how people respond to serious illness, rather that focusing on the determinants of the decision to perform a behaviour. These will not be considered. In contrast, the second type of social cognitive model specifically seeks to predict future health behaviour on the basis of appraisal and processing of available information. The most widely cited social cognitive models that address cognitions involved in making a decision are: Health Belief Model, Protection Motivation theory, Theory of Reasoned Action/ Theory of Planned Behaviour, Social Cognitive Theory, Stage models of health behaviour change (Transtheoretical model of change and Precaution adoption process model).

Therefore, in this section, the Health Belief Model, Protection Motivation Theory, Social Cognitive Theory and the Stages models are briefly described and rejected as candidates on the basis that they may not be applicable to the behaviours under consideration. The Theory of Planned Behaviour is presented in greater detail and its appropriateness for this research is discussed.

3.13 Health Belief Model

Rosenstock (1966) proposed the health belief model (HBM), which is one of the oldest and most widely used theories to explain people's health-related behaviour. The HBM posits that the likelihood that individuals will perform behaviour is a function of an individual's perception of: susceptibility of illness, the severity of illness, the costs and benefits involved in carrying out the behaviours. Janz & Becker (1984) added cues to action, which may be internal or external. Criticisms of Rosenstock's (1966) original model led to revisions, which included the constructs of health motivation (to reflect an individual's readiness to be concerned about heath matters) and perceived control.

Research into health behaviours using this model have been extensive (see Conner & Norman, 1996). Overall the health belief model is a good predictor of whether people engage in health-related behaviours (Rosenstock, 1990). The HBM has provided a useful framework for research in the area of health behaviour prediction, with moderate success in predicting a wide range of health behaviours (Harrison, Mullen, & Green, 1992; Janz & Becker, 1984; Sheeran & Abraham, 1995). The common sense operationalisation of the model's cognitive variables also account for the popularity of the model. To date, there has been no research conducted using this model to predict advance care planning, or to predict communication behaviours.

Although the results using the HBM have been favourable, researchers have raised some interesting questions about its usefulness. It has been argued that the HBM is more a collection of variables than a formal theory or model (Oliver & Berger, 1979). Further, research suggests that not all components of the model have proven to be useful in predicting variance in behaviour (see Edelmann, 2000). The HBM has some conceptual difficulties. Rosenstock did not specify how different beliefs influence one another, or how the explanatory variables combine with one another. As a result, different studies have used different combinations of variables and researchers have treated variables differently in the analysis. Some, for example, have combined variables, by adding vulnerability and susceptibility, or by multiplying them or subtracting barriers from benefits (see Rutter & Quine, 2002).

The model does not include other social cognitive variables that have been found to be highly predictive of behaviour (e.g. intentions, social pressure, perceptions of control). Furthermore, the model fails to provide the theoretical framework for more powerful data analysis to suggest clear targets for behavioural interventions, due to the lack of consensus about the causal ordering of the variables within the model. Finally, the HBM has been criticized for being a static model. The model fails to distinguish between a motivational stage, where cognitive elaboration will lead to a decision on the goal to be pursued, and a volitional stage of action planning, performance and maintenance (Schwarzer, 1992).

In addition to the conceptual and methodological problems, there were various reasons why it was not chosen to study advance care planning. Firstly, according to Ogden (2004) the HBM focuses on conscious processing of information and does not take into account social and economic factors. As suggested previously, predicting advance care planning involves taking into account the perceptions of significant others and also the broader social context. These important issues are not included in the HBM. Secondly, the model fails to take into account emotional factors such as fear and denial. Making decisions on whether to prolong life involves thinking about life and death, which are issues that people are fearful of and often deny. Also, the model does not take into account the component of self-efficacy, or a person's confidence that they can effectively engage in the behaviour (Schwarzer, 1992). More recent theories such as Theory of Planned Behaviour and the Social Cognitive Theory have included this component. Lastly, it was envisaged that defining the predictors of advance care planning using variables from the HBM would be difficult for older people living in the community, particularly as they were not necessarily ill or facing a resuscitation order. Therefore for them to conceptualise problems of susceptibility and severity would be difficult, particularly as issues of death are denied and feared. Therefore for a complex emotionally laden behaviour, which takes into account various social factors, HBM was not considered as useful.

3.14 Protection Motivation Theory

This theory was developed to provide a conceptual framework in understanding fear appeals (Rogers, 1975). The most typically applied version of the theory proposes threat appraisal and coping appraisal as the two appraisal processes determining the (adaptive and maladaptive) coping with a health threat (Maddux & Rogers, 1983; Rogers, 1975). Threat appraisal is determined by perceptions of susceptibility to illness and severity of the health threat, whereas coping appraisal involves the assessment of the action alternatives that might reduce the threat. Coping appraisal is determined by the expectancy of diminishing the threat by carrying out the particular action (action-outcome expectancy), and by the belief in one's capacity to successfully execute the recommended action (self-efficacy).

Protection Motivation Theory (PMT, Rogers, 1975) incorporates the health belief model but also makes use of Bandura's concept of self-efficacy. Decisions to engage (or not engage) in health-related behaviour are mediated by the amount of protection motivation aroused, which has the ability to sustain and direct activity. PMT claims that health related behaviour is a product of behavioural intention which is related to the following components: *severity*; susceptibility; response effectiveness and self-efficiency. Rogers (1985) suggested a role for a fifth component: fear (e.g. an emotional response). PMT describes severity, susceptibility and fear as threat appraisals (i.e. appraisal of outside threat). Self-efficacy and response effectiveness are described as coping appraisals (i.e. appraising the individual themselves). According to PMT, two types of information influence the components – environment information and interpersonal experience. Rogers (1975) argues that individuals are influenced by information, which leads to an 'adaptive' coping response (e.g. forming a behavioural intention) or a 'maladaptive' coping response (e.g. avoidance or denial).

The PMT has been successfully applied to research in the prediction of various health behaviours (see Conner & Norman, 1996). A number of revisions have been suggested in the literature, the core one being the one proposed by Maddux and Rogers (1983). This theory has been described as a hybrid theory, as it consists of an amalgam of concepts in the health belief and the self-efficacy models (see Conner & Norman, 1995, p.11). More particularly, susceptibility, severity and action-outcome efficacy are components of the HBM, whereas self-efficacy is a component of the self-efficacy theory (Bandura, 1977).

Research has shown that the threat appraisal components are weaker determinants of intentions and behaviour, in comparison to the action-outcome efficacy and self-efficacy. It has been proposed that this may be due to the fact that it is a more distal predictor that plays a role in a more initial stage of the decision making process through its effect upon action-outcome expectancies (Weinstein, 1988). More recent versions of the model have included internal and external rewards from the current behaviour and perceived costs of the revised behaviour (Rippetoe & Rogers, 1987). Despite the inclusion of many of the important cognitive determinants of health behaviour performance, variations in the theory's conceptualisation and operationalisation have detracted from its explanatory power. Even though PMT takes into account self efficacy, the effect of environmental information, such as media coverage and components of fear, it fails to address broader social factors such as the thoughts that one may have about significant others' (family and doctors) views on the behaviour. Thus the main reason for rejecting the theory was the fact that it neglected the social context of these cognitions.

3.15 Social Cognitive Theory

Social cognitive theory posits that people acquire attitudes through various sources of their immediate social networks as well as by observing people presented in the media (Bandura, 1977, 1986). 'Direct modeling' occurs when people observe others in their social networks engaging in particular behaviours, whereas "Symbolic modeling" occurs when people portrayed in the media are observed. However, whether these attitudes lead to behaviour change is a function of people's beliefs about their own ability to engage (or not engage) in a particular behaviour (self-efficacy) and the beliefs about the consequences of engaging (or not engaging in the behaviour) (outcome expectancies).

Social cognitive theory includes an individual's self-efficacy, namely, the extent to which one believes he or she can engage in a particular behaviour. This is similar to the Theory of Planned Behaviour's concept of perceived behavioural control. Self-efficacy can influence behaviour in two specific ways (O'Leary, 1992). First, people who have a strong sense of self-efficacy for a given behaviour are likely to exert considerable effort to perform the behaviour. Second, research shows that people with low self-efficacy have a greater physiological response to stressful situations (such as making difficult changes in their behaviour), including higher heart rates and blood pressure, than people with low self-efficacy. This greater anxiety response may lead people with low self-efficacy to be less likely to even attempt to engage in the behaviour (see Sanderson, 2004). Finally, people with higher self efficacy show a higher correlation between knowledge and behaviour (Rimal, 2000). The social cognitive model also takes into account the component of outcome expectancies; an individual's beliefs about whether engaging in a particular behaviour will have a desired outcome.

Although the model has some desirable features for the present research it also has some limitations. It does not include emotional components either directly or indirectly such as by including attitudes. Despite the emphasis on self-efficacy, other cognitive determinants of health behaviour are not included, such as intentions, or normative beliefs. Therefore, it was not viewed as the best theoretical approach.

3.16 Stage model of health behaviour change

Some critics of the models reviewed above suggest that the models are too simplistic in their characterization of health behaviours. Health behaviour change is a complex process, occurring gradually in stages. Consequently, alternative models have been proposed that focus on the steps involved in making a behaviour change. These models specify a set of ordered categories or stages that people go through as they attempt to change their behaviour. The Transtheoretical model of behaviour change and the Precaution Adoption Process Model are two examples of such stage models. These will be briefly described, and their limitations for the present research discussed.

3.16.1 Transtheoretical models of behaviour change

Prochaska & DiClemente (1982) developed the transtheoretical model of behaviour change (or the stages of change model) from a synthesis of 18 therapies that describe the processes involved in eliciting and maintaining change. They suggested a model of behaviour change related to the individual's state of readiness to change based on the following stages: *precontemplation*, (i.e. not intending to make any changes), *contemplation*, (i.e. considering changes in behaviour), *preparation*, (i.e. getting ready to make changes), action, (i.e. actively engaging in behaviour change), *maintenance*, (i.e. sustaining the change for longer than 6 months). These stages were not considered to occur in a linear fashion, but rather the model described behaviour changes as a dynamic process, with the individual moving back and forth between stages possibly several times before the action and maintenance stages are achieved. Thus, importantly, the models incorporate the notion of lapse and relapse as part of the process of change. The model also examines how the individual weighs up the costs and benefits of a particular behaviour and suggests that individuals at different stages of readiness will differentially focus of either the cost of the behaviour or the benefits of the behaviour.

3.16.2 Precaution Adoption Process Model

The precaution adoption process model is similar to the transtheoretical model as it also proposed that when individuals consider engaging in a new health related behaviour they do so through a series of stages. The model includes seven stages. In stage 1, people are not even aware of the disease or problem. In stage 2, people are generally aware of the health risk and believe that others might be at risk, but they do not believe that they are at risk. In other words, they may have an optimistic bias about their own levels of risk. In stage 3, the decision making stage, people have acquired a belief in their own personal risk, but they still have not decided to take action to protect themselves from the risk. Individuals can move directly to stage 5, where they decide to take action, or move to stage 4, where they decide that action is unnecessary. In stage 6, individuals start making changes to their behaviour and finally in stage 7 people maintain the behaviour change over some period of time.

The transtheoretical model and the precaution adoption process model have certain limitations which made it an unsuitable candidate to be used in this study. The transtheoretical model is relatively new and had been widely studied with respect to issues of smoking and substance abuse (e.g. DiClemente & Huges, 1990). However, the cognitive processes involved in leading people to stop certain behaviours are different from getting people to start behaviours (e.g. Rosen, 2000). Similarly, the precaution adoption process model has been used for smoking cessation and other behaviours where individuals are aware of a threat or risk. Therefore, its applicability to studying the initiation of a new behaviour, which they may not be familiar with, rather than stopping behaviour was not considered favourable. In addition, the interest was on healthy older people living in the community, who did not have adequate knowledge or may see a risk of not engaging in the behaviour. Further, these models have been primarily used as a basis of designing intervention. This study was concerned with understanding why people undertake or do not undertake behavioural change. Despite highlighting the stages that an individuals may go through which engaging in behaviour change, these models do not give an indication of the variables that are important when making these changes to the different stages. Therefore, stage models were rejected as candidates for studying resuscitation decision making and advance care planning.

3.17 Theory of Planned Behaviour

The Theory of Planned Behaviour (TPB) was proposed by Ajzen (1985, 1988 & 1991) as an extension to the Theory of Reasoned Action (TRA). The theory of planned behaviour added the component of perceived behavioural control (PBC) to the theory of reasoned action. Consistent with Bandura's (1977) work on self- efficacy expectations, the theory incorporates the construct of perceived behavioural control that deals with people's perceptions of control over the behaviour. That is, their beliefs that they can perform the behaviour if they so desire, that they do have the required skills and other resources. Consideration of perception of control is important because it extends the applicability of the theory beyond easily performed, volitional behaviours to those complex goals and outcomes which are dependent upon performance of a complex series of other behaviours.

The TPB was designed to provide an explanation of informational and motivational influences on behaviour. Therefore it is a deliberative processing model, implying that individuals make behavioural decisions based on careful consideration of available information.

According to the theory, human behaviour is guided by three considerations:

- beliefs about the likely outcome of the behaviour and the evaluation of these outcomes (*behavioural beliefs*);
- beliefs about the normative expectations of others and motivation to comply with these expectations (*normative beliefs*);
- and beliefs about the presence of factors that that may facilitate or impede performance of the behaviour and the perceived power of these factors (*control beliefs*).

In their respective aggregates, behavioural beliefs produce a favourable or unfavourable *attitude towards the behaviour*; normative belief result in perceived social pressure or *subjective norms*; and control beliefs give rise to *perceived behavioural control.* In combination, the attitudes towards behaviour, the subjective norms and the perceived behavioural control lead to the formation of a behavioural *intention.* As a general rule, the more favourable the attitude and subjective norm, and greater the perceived control, the stronger the person's intention to perform the behaviour in question will be. Finally, given a sufficient degree of *actual control* over the behaviour, people are expected to carry out their intentions when the opportunity arises. Intentions are thus assumed to be the immediate antecedent of behaviour. However, as some behaviours pose difficulties of execution that may limit volitional control, perceived behavioural control is considered in addition to intention. Perceived behavioural control can serve as a proxy for actual behaviour and contribute to the prediction of the behaviour in question. A diagrammatic representation is included in Fig. 3.1:

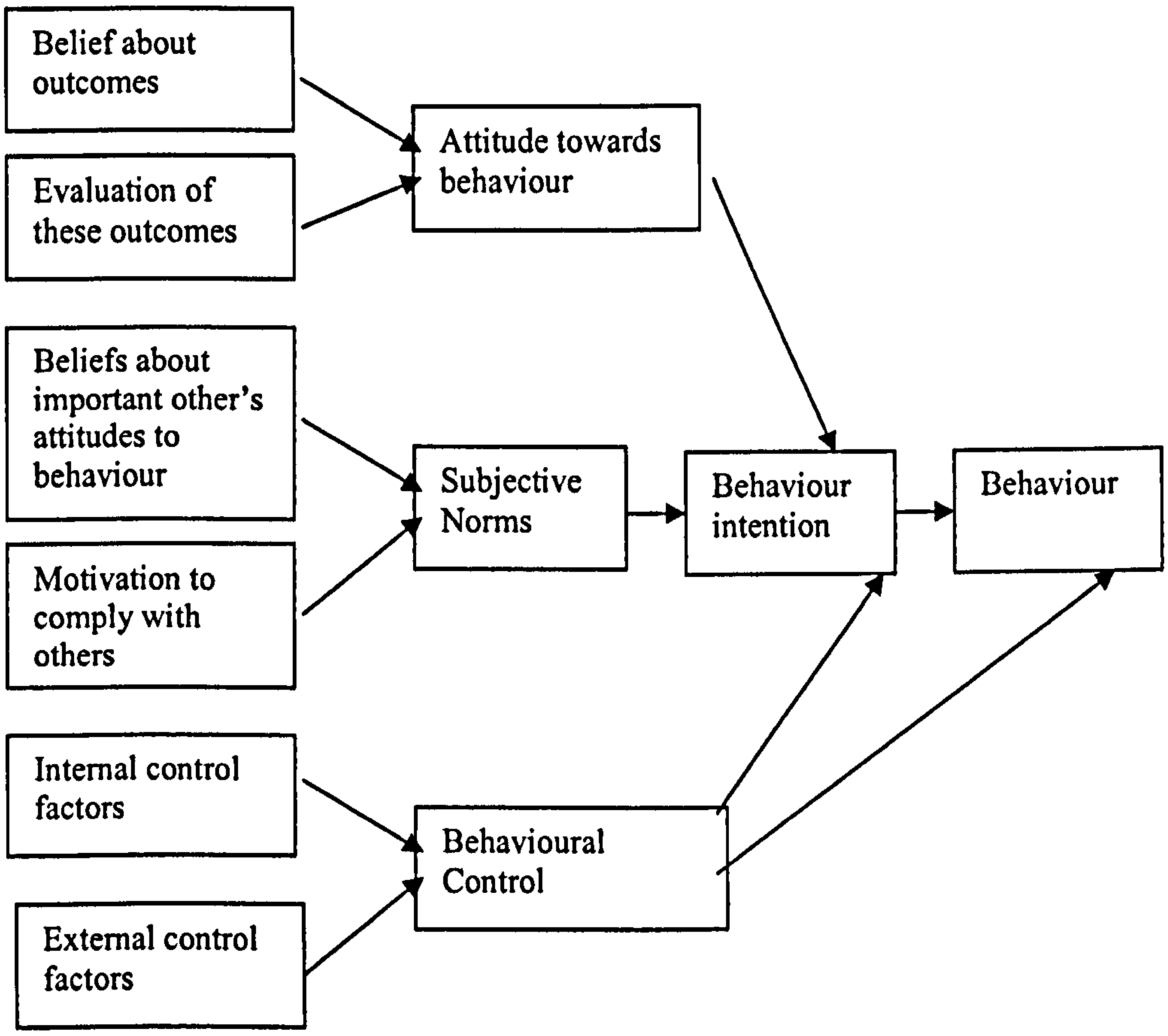

Figure 3.1: Diagrammatic representation of the Theory of Planned Behaviour (TPB).

The TPB has had an enormous influence on the literature concerned with the prediction of intentions and behaviour and health behaviours (see Conner & Norman, 1996, for a review). It has been used for a wide variety of behaviours including various novel behaviours (such as testicular and breast self-examinations). In the last decade the TPB has been one of the most widely applied social cognition models, due to the interest by the research community in identifying social cognition variables determining health behaviours that may be susceptible to change (Rutter & Quine, 2002). Meta-analytic reviews of the TPB provide strong support for the predictive validity of the TPB in terms of the percentage of variance explained in behaviour and intentions by the components of the TPB.

Two recent meta analytic reviews indicate that the TPB is a powerful predictor of intentions and behaviours, although more powerful for predicting intentions. The first of these meta analyses (Godin & Kok, 1996) reported that that the TPB can account for 41 % of the variance in intentions (R=.64, 76 correlations) and 34 % of the variance on behaviours (R=.58, 35 correlations) for a range of health behaviours. The more recent review (Armitage & Conner, 2001) concluded that the TPB variable accounted for between 27 % and 39 % of the variance in behaviour and intention respectively. Both these reviews suggest that TPB is as a powerful model in predicting intention and behaviour.

The TPB was considered a good theory to study research on older people's decision making about resuscitation and advance care planning. TPB has variables that could be used to conceptualise the problem and the prediction of these behaviours. The model takes into account the rational and deliberate act of decision making, where the individual makes decisions on whether to engage in advance care planning based on an assessment of various factors. These factors include an emotional or evaluative component where the individual takes into account their attitudes towards resuscitation decision making, and their attitudes towards death and dying. Research using the TPB found that attitudes influence an intention to perform (or not perform) a behaviour which in turn predicts behaviour.

Furthermore, the theory accommodates the broader social context for the decision, with its inclusion of subjective norms. This takes into account the influence of the family, doctors and the media when making decisions on life prolongation. Research using the TPB has found that in the absence of intentions, subjective norm is the strongest predictor of behaviour (Rutter, 2000). In the study of particular behaviours, the perceived pressure from others outweighs one's own attitude to the behaviour and in this study where the approval from others may be important, it was considered essential to include a model which included the normative influence of behaviour.

More importantly, the role of perceived behavioural control over intentions and behaviour are taken into account in this model. The relationship suggests that individuals are more likely to engage in desirable behaviours that they have control over. It also suggests that individuals are prevented from carrying out behaviours over which they have no control. Perceived behavioural control (PBC) serves to greatly increase the model's predictive value (Armitage & Conner, 2001). PBC not only influences intentions but also has a direct influence on behaviour. This is of particular relevance to the topic under investigation as it was envisaged that control or efficacy to perform the behaviour would strongly influence the behaviour choice. A wish to have control over the dying process by investing in advance care planning may strongly influence intention to perform the behaviour as well as performing the behaviour. Lack of control due to not having enough medical knowledge about the efficacy of CPR may leave older people with no intention to perform the behaviour.

The model takes into account people's intention to perform or not perform behaviour. Studies have shown that there is a strong link between intention and behaviour, with intention being the strongest predictor of behaviour, accounting for 20-30 % of the variance in social and health behaviours (Rutter, 2000; Sheeran & Orbell, 1999).

Lastly, recent literature has shown that there have been some interesting theoretical developments, including ambivalence of attitudes (Conner & Sparks, 2002), inclusion of other variables such as past behaviour (e.g. Norman, Conner, & Bell, 2000; Sutton, Bickler, Aancho-Aldidge & Saidi, 1994) and perceived behavioural need (e.g. Povey, Conner, Sparks, James & Shepard, 2000) and the conceptual distinction between 'goal intentions' and 'implementation intentions' (Gollwitzer & Brandstatter, 1997). These new developments and the growing empirical evidence to support their addition to the TPB offer some understanding of the processes by which they may be related to the TPB variables of intentions and behaviour.

Therefore the TPB within the paradigm of social cognitive models was chosen as an adequate framework to guide research, from design and measurement to analysis and understanding the results. However this choice was made with some misgivings. In the following section, criticisms of using the social cognitive approach will be briefly described.

3.18 Criticism of social cognition models

Social cognitive models (SCMs) have been criticized for not providing an adequate description of the way in which people make decisions (see Conner & Norman, 1995; Feather, 1982; Edwards, 1992; Jonas 1993). SCMs provide a clear theoretical framework for understanding health behaviours. There is, however a danger of neglecting the influence of variables that are external to these models (Conner & Norman, 1995, p.15). The TPB in particular assumes that the theory's variables mediate the influence of variables not included in it. However, there is evidence against this tenet (e.g. see Rhodes & Courneya, 2003 on the direct effect of the activity facet of extroversion on exercise behaviour). There are various, behaviour-specific variables (cognitive and non-cognitive) that may play an important role in the prediction of each behaviour. Therefore, the application of the SCM should take other variables into consideration to improve the model and add to its predictive power. Fishbein (1993) suggested that even the most well-established SCM is open to revisions that are theoretically and empirically justified.

SCMs have added to our understanding of the motivational processes underlying human behaviour. However, most of them do not address the impact of volitional processes that will translate intentions to behavioural enactment (Conner & Norman, 1995). Further developments are necessary to increase the limited research addressing the gap between intentions and behaviour (Bagozzi, 1993; Gollwitzer, 1997; Norman & Conner, 1996; Schwarzer & Fuchs, 1995).

Marks and colleagues (2000) have criticised the SCM's for a variety of reasons. Firstly, SCM's are only concerned with cognitively mediated behaviours. Secondly, they do not take into account direct effect of impulse and/or emotion. For example, situational pressure such as physical and emotional 'urges' or power relations can have a strong and direct effect on health relevant behaviours such as contraceptive use and safer sex practices (Ingham, Woodcock & Stenner, 1992).

Thirdly, they assume that the same variables inform different behaviours. However, the predictive power of any one SCM varies depending on the context of its applications, where different variables appear to have different predictive power for different behaviours. Fourthly, SCM's assume that the same variables are relevant for diverse groups of people. Literature suggests that the psychological antecedents of behaviour differ for different people. Fifthly, they focus exclusively on the mental representations of the social world and do not account for the direct effects of material, physical and social factors. For example, lack of access to health resources is featured as lack of volitional control, thus maintaining the focus upon the individual, as opposed to his/her social and material location, physical and social factors can place great constraints to the individual's ability to act upon information. Moreover, frustration and hopelessness due to lack of access to resources can lead to decrements in well-being and therefore influence the performance of a behaviour. Finally, SCMs have been criticised for not addressing the issue of joint decision making. Decisions about health-relevant behaviours are conceptualised as individual ones. However, many health behaviours arise out of an interaction between two or more people, and the individual level of analysis may be too narrow for a theory of behaviour change.

Another area of criticism relates to the extent to which thought or cognition precedes action. Some behaviour seems to occur without conscious awareness or without much conscious thought about the details of the performance. Social psychologists have also noted the problem about cognition and behaviour and the extent to which apparently thoughtful action is mindless (see Feather, 1982, Nisbett & Wilson, 1977; Weiner, 1980). It has been argued that even in situations where there is little thought about the precise mechanisms of response, thoughts about the goal structure and the general planning of action in relation to this goal will almost certainly occur. Furthermore, action is often punctuated by choice points and decisions or blocked by obstacles, one would also expect to find evidence of increasing cognitive activity.

Feather (1982) has responded to some of these concerns and criticisms of SCMs. The social cognitive approach has been criticised as being too normative in its emphasis, ignoring the widespread defects and errors known to take place in information-processing, and focusing on 'cold' cognitive appraisal rather than the 'hot' cognition occurring under stress or high emotional involvement. Feather (1982) responded in this criticism by arguing that this is rather a misreading of the social cognitive approach. The variables in the model are cognitive in nature and they may be in error at any given time when tested against objective reality. The model accepts the subjective reality as important for understanding a person's behaviour -however defective it may be- and recognises that motivational and emotional states can distort or even disrupt the thought process, so that behaviour may appear to be irrational. Moreover, the model is not normative in that it prescribes how decisions ought to be made and pays little attention to how they are made. On the contrary, the model has been applied to behaviour as it occurs, and often in situations of relatively high involvement.

More recently, Ogden (2003) suggested that there are conceptual limitations regarding a number of the most popular social cognition models. More particularly, she suggested that based on a review of the most recent literature (1997-2001) in pragmatic terms these models seem to be useful in guiding research. However, in conceptual terms these models include unspecific constructs which do not enable testing the hypotheses set. Moreover, she proposed that social cognition models focus on analytic, rather than synthetic truths that lead to conclusions that are true by definition, rather than observation. Finally, she suggested that these models may create and change people's cognitions and behaviour rather than describe them. Ajzen and Fishbein (2004) responded to this critique by arguing that the findings proposed by Ogden (2003) as demonstrating the limitations of the social cognition models are actually consistent with them. They also argued that there is good evidence of the validity of the measures used to asses the validity of the constructs incorporated in the theories and that the argument regarding the effect of completing a questionnaire needs empirical support.

From a social constructionism perspective, Stainton-Rogers (1991) criticised SCMs in that they portray thinking as 'a passive, mindless activity rather than an active striving after meaning, and portray people as thinking machines rather than as aware and insightful, open to being beguiled by convincing tales and rhetoric, and inventive story tellers' (p.55). From a social interactionism perspective, SCMs have been criticised for leading to an individualistic focus in health promotion, because they view the thinking process as taking place inside the person's head and not as something that unfolds as a result of the interaction with others. According to this approach, the individual is part of a group and of a society and cognitions and behaviour can be therefore explained as resulting from the continuous interaction with the groups and the society as a means of adapting to changing circumstances.

3.19 Conclusion

Despite the above concerns, the TPB was regarded as the best candidate as a theoretical framework for investigation older people's views on resuscitation and advance care planning. The researcher however acknowledges the criticisms of the social cognitive approach. In response to some of the concerns regarding the use of the TPB, a decision to use a qualitative approach to complement the traditional quantitative approach, in which much of the research on SCMs have been conducted, was made. The case for mixing both qualitative and quantitative methods in the study of older people's views on resuscitation and advance care planning will be made in the next chapter.

Chapter 4:
Epistemological and methodological issues

4.1 Introduction

The researcher's epistemological position will be introduced in this chapter. Smith (1990) suggested that the epistemological position of the researcher is central to the proper understanding of a piece of research as epistemology, methodology and research questions are interlinked. Harding (1987, p 2-3) pointed out that the epistemological position (a theory of knowledge or strategies for justifying beliefs) should be distinguished from research methodology (ways of proceeding in gathering evidence) and in turn from any specific method adopted (research strategy or technique). In other words, epistemological position, depending on the framework for the 'acquisition of knowledge' in which the researcher works, determines the choice of method, the choice of the research programme and finally the choice of theory the researchers want to test with adequate method. Therefore the researcher's epistemological position will be made explicit. A brief description of qualitative and quantitative methods and a discussion of their underlying epistemologies will follow. The case for choosing a multi-methodological approach will be given. This will be followed by a detailed account of the research strategies adopted by the researcher. Further, the criteria used for assessing good practice will be discussed and a personal reflection of the motives for embarking on this topic will be described.

4.2 Comparing quantitative and qualitative methods

Historically, the academic psychologist's epistemological position is derived from the natural sciences and is based on the hypo-deductive model of knowing (by which causal relationships are tested), with its rules of objectivity, generalisability, replicablity, reliability and validity. Within this 'positivist' doctrine, the researcher uses experimental manipulation and control of subsets of variables to test a 'prior' theory. Quantification is important as the testing of theories is normally carried out on large numbers of cases to eliminate individual variation and hence a statistical approach is considered appropriate. This is traditionally a positivist model of science, which considers that theories are value free. Positivism refers to a particular 'philosophical attitude to human knowledge and does not pose questions of how people arrive at knowledge (either psychological or historical foundations of knowledge) but is a collection of rules and evaluative criteria referring to human knowledge' (Hammersley, 1993, p.2).

However since the 1960's some psychologists, especially those dealing with social phenomena, have become dissatisfied and disillusioned with the products of a purely quantitative approach to human nature and have opted for a more naturalistic, contextual and holistic understanding of human beings in society. In qualitative research, the generation of hypotheses replaces the testing of hypothesis, explanation replaces measurement and understanding replaces generalisability (Jones, 1995). These qualitative methods focus on the interpretative (or hermeneutic) understanding of the meaning of actions and institutions. Psychology, along with other social sciences, acknowledges the importance of cognition – an individual's understanding of their world – in the explanation of social behaviour. Qualitative methods are concerned with the construction of reality. This idea is also known as 'social constructionism' or 'social constructivism'; where the individual is seen as actively constructing knowledge, self, understanding, reality and truth in social interaction with others (Todd, Nerlick, McKeown & Clarke, 2004).

Social constructionism starts with the idea that realities are actively produced by the participants through the meaning ascribed to certain events and thus to study social realities the researcher must ascribe meanings to these social realities. Therefore, social constructionists claim that science creates knowledge and truth, rather than discovering knowledge (as claimed by quantitative researchers). Not only are multiple realities constructed in social interactions between people, social interactions between researchers construct multiple accounts of these realities. Bryman (1988) suggests that qualitative researchers prefer 'an approach to the study of the social world which seeks to describe and analyse the culture and behaviour of humans and their groups from the point of view of those being studied' (p.46). The central position of the researcher in the construction of knowledge is acknowledged, suggesting that it has a reflexive quality (Banister, Burman, Parker & Tindal, 1994). This reflexivity bridges the gap between the subject (investigator) and the object (investigated) (Banister et al., 1994).

Qualitative and quantitative methods could be alternative approaches, used for differing psychological problems; instead they have become entrenched ideological or epistemological positions (Todd et al., 2004). Belonging to distinctively different paradigms and two apparently opposed epistemological positions, quantitative research, based on a positivist paradigm is experimental, deductive, numeric and realist. Qualitative research, on the other hand, is based on an interpretative paradigm, is naturalistic, inductive, contextual and non-numerical, interpretative and constructionist (Henwood & Pigeon, 1992; Richardson, 1994), and is considered the antithesis of quantitative data.

Due to their particular characteristics, some researchers consider the two methods as contradictory and fundamentally different, and rigid demarcations do not encourage movement between the two traditions (Pope & Mays, 1995). Quantitative and qualitative researchers operate within different sets of assumptions about the world and ways of learning about the world (Casebeer & Verhoef, 1997). Researchers of the different paradigms are often ignorant of each other's work and argue that their particular approach is best (Sarantakos, 1998). However, other researchers suggest that quantitative and qualitative methods are extremes of the same viewpoint and maintain that every research project, although predominantly one or the other, contain aspects of both methods (Hammersley, 1992; Saranakos, 1998).

It is important to avoid viewing qualitative and quantitative methods as deriving from non- equivalent paradigms, and to see them as not mutually exclusive, but complementary rather than competitive (Jones, 1995; Richardson, 1994). Hence, it has been suggested that both qualitative and quantitative methods should co-exist as potential tools of the research trade (Casebeer & Verhoef, 1997; Yardley, 1999). This 'mixed method' approach, which is increasingly being used in health research, can approach the same topic by investigating different research questions, collecting different types of data and producing different answers (Jones, 1995). Therefore it has been suggested that the research is strengthened through the use of principled mixture of methods (Henwood & Pidgeon, 1992).

4.3 Methodological pluralism: A case for a multi-methodological approach

The aim of this research is to gain an understanding of the factors that influence older people's views on resuscitation and advance care planning – to provide a descriptive and a causal account of their perspective. In approaching this task, the researcher takes a pragmatic position, with the research process primarily seen as a practical rather than political activity. Understanding the internal world of individuals is not only tied to an epistemological preference, but to the job of uncovering of new understandings (see Hammersley, 1995). Bryman (1988) suggests that 'the distinction between qualitative and quantitative research is really a technical matter whereby the choice between them is to do with their suitability in answering particular research questions' (p.108-109).

This research adopts a constructivist position in that it sees the 'reality' experienced by the participants as being shaped by the meanings they attribute to their social, physical and cultural environment. A strong constructivist approach leads to relativism and the conclusion that no one interpretation has priority, or a closer claim to 'truth' than another. In this research, the author adopts the weak constructivist position, which claims that there are criteria for judging between some competing accounts of a situation and that rigour of good practice (to be discussed later in the chapter) will lead to conclusions that are plausible and theoretically useful.

The weak constructivist position adopted by the researcher does not preclude the use of quantitative methods (see Hammersley, 1996; Miles & Huberman, 1994). The mixed methodological approach has been used here for a variety of reasons. Firstly, the qualitative approach was viewed as the best way to conduct a preliminary study to assess whether the area of investigation would be plausible, whether older people considered advance care planning relevant and whether they would discuss these sensitive and potentially distressing issues. The findings of this study were used to inform and expand the Theory of Planned Behaviour (Ajzen, 1991), which was used to predict intentions and behaviour for advance care planning. Further quantitative and qualitative studies were then conducted to allow the possibility of strengthening this research by providing a triangulation of methods addressing a particular question, namely how older people decide on advance care planning. Todd et al. (2004) argue that using triangulation of two methods 'creates a more accurate picture of what is going on and increases confidence that those results are a true representation, as opposed to a fluke due to flaws in the method used' (p. 9). Triangulation of methods is recommended to reduce validity concerns (Stiles, 1993). In order to provide for triangulation, it was decided at the outset that qualitative methods (focus groups, in particular, see chapter 7 for details) would be used to test phenomenological validity of the findings of the quantitative study (see chapter 6) and to provide a context to the questions being addressed. Yardley (1999) recommends for researchers to overcome dualistic bias, suggesting that there is no single correct view of the world, and phenomena have different meaning and implications for different people under different contexts. This respect for diverse opinion frees researchers to explore the values and significance of a variety of perspectives, thus enriching the understanding of the topic of research. In addition, quantitative methods (see chapter 8) are used to test specific, focused, theoretical research questions, which evolved from the earlier analysis. The last study (see chapter 8) employed a quantitative approach to explore and compare older people's and confidants' views on resuscitation and advance care planning.

Finally, it was assumed that the use of a mixed approach would safeguard against claims of 'depopulation' (Billig, 1994). Billig argued against the 'depopulation' of psychology, by which people become subjects and the relationship between the researcher and the researched is not taken into account. Ussher (1994) claims that a largely quantitative approach has led to issues such as gender and race being ignored. Therefore taking into account the context, paying attention to subjective elements and considering issues of reflexivity strengthens research. Todd et al. (2004) suggest that mixed-method research requires psychologists to consider these issues in the design and analysis of studies, as well as to take a deeper look at the theories framing (or arising from) the work. For such a sensitive topic as the one investigated here, it seemed particularly important not to risk "depopulation" and investigate these issues with the context on an individual's socio-economic and historical background.

4.4 The research strategy

In approaching an area which addressed sensitive issues, the researcher was faced with the question of whether older people living in the community would be willing to discuss sensitive issues regarding life prolongation. As mentioned earlier (in Chapter 3), there has been little research exploring healthy older people's perspectives of life prolongation in the UK. Therefore to assess the feasibility of the topic under investigation and to explore the factors that healthy older people considered important, content analysis was chosen as the initial method of investigation. The themes emerging from this analysis were used to inform and expand the Theory of Planned Behaviour (which was used in the next empirical study, see Chapter 7) to explore older people's intentions and behaviour with regard to advance care planning. Later in the thesis, Interpretative Phenomenological Analysis (IPA) was used to explore phenomenological validity of the findings in the quantitative study. At this stage, the work was inductive to the extent that the researcher will attempt to make sense of the phenomena under investigation, without imposing pre-existing expectations in the research setting. Categories or dimensions of analysis emerge from the data as the researcher comes to understand the data processes. Hence, this study was not guided by hypothesis but by questions, issues and a search for patterns or themes.

Content analysis, IPA and multivariate statistics were used in the present work and they complimented the epistemological position of the researcher. Content analysis and interpretative phenomenological analysis (IPA) bear remarkable similarities. However, they differ in other characteristics. Content analysis involves identification of important themes and patterns in the data and making the information explicit. Data is hence classified by defining a unit of analysis as a word, phrase, or a sentence. The purpose of content analysis is the organisation and simplification of complex data into meaningful and manageable categories. In contrast, IPA assumes that patterns, themes and categories come from the data; they emerge out of the data rather than being decided prior to data collection and analysis. The research hence looks for natural variations in the data, i.e. the researcher pays attention to processes under investigation, and interpretation is an integral part of the research. Therefore, both methods focus on a search for patterns and themes; content analysis assumes that themes are already in the data, while inductive analytic methods assume that they emerge from the data. In addition, content analysis view categories as mutually exclusive, while in IPA, the overlap of themes and sub-themes and the non-mutually exclusiveness of the themes are accepted.

The aim of IPA is to explore in detail the participant's view of the topic under investigation. The term phenomenological is used as the method it is concerned with an individual's personal perception or account of an event as opposed to an attempt to produce as objective statement of the event itself (Smith, Jarman & Osborn, 1999). The researchers' own conceptions are used to make sense of the data through a process of interpretative activity. Hence the dualistic component of IPA is concerned both with the individual's personal perceptions and the researchers' interpretation of the data. IPA adopts a weak social constructionist epistemological position, similar to that of the researcher as it emphasises that 'reality' is more appropriately regarded as constructed in interaction between the researcher and the participant (Murray & Chamberlain, 1999). IPA accepts the impossibility of gaining access to research participants' life worlds. Even though IPA explores the research participant's experiences from his or her perspectives, it recognizes that such an exploration must necessarily implicate the researcher's own view of the world as well as the interaction between the researcher and the participant. As a result, the phenomenological analysis produced by the researcher is always an interpretation of the participants' experience. In addition, Willig (2002) suggests that IPA adopts a contextual constructionist viewpoint as it assumes that 'research is based upon the assumption that all knowledge is necessarily contextual and standpoint dependent' (Willig, 2002, p. 145).

Much of the theoretical work in the field of death and dying has used Grounded Theory approaches as a means of approaching the process of theory development (see Owens & Payne, 1999). Grounded theory is primarily used where there is recognition of a lack of coherent theoretical perspective and is essentially empirically driven. However, in this case, data were gathered to test and provide phenomenological validity to an existing theoretical model, namely the Theory of Planned Behaviour. Theoretical sampling, an essential component of the grounded theory approach was not considered feasible and practical; however purposeful sampling was used with the motive of eliciting as many diverse views about end-of-life issues and attitudes towards death as possible. For these reasons it was considered more appropriate to use IPA.

IPA fits with the social cognitive stance taken by the researcher, based on the premise that people's thoughts and beliefs are reflected in the way they talk about them, which is the basis of the social cognition paradigm. According to IPA, an individual is the owner of a set of cognitions (ideas, beliefs, expectations, etc.) which he or she uses to make sense of the world and to act in the world (Willig, 2002). Smith (1996, p. 263) argues that IPA is concerned with cognition because it is concerned with understanding 'what the participant respondent thinks or believes about the topic under discussion'. He proposes that IPA is compatible with a social cognition paradigm because it subscribes to 'belief in, and concern with, the chain of connection between verbal report, cognition and physical state' (Smith et al., 1999, p. 219).

4.5 Demonstrating good practice

Within the positivist assumption that there is truth out there that is defined as having some form of correspondence with reality, the researcher's commitment to the rules of objectivity, generalization, replicability and validity are clearly defined. However, concepts such as reliability, validity and generalisability are often seen as irrelevant in the evaluation of qualitative research, as they are based on assumptions central to the positivist perspective. Instead researchers look for credibility, dependency, trustworthiness, transferability and authenticity (Denzin & Lincoln, 1994). These evaluative criteria do not de-contextualise the data; on the contrary, qualitative research is firmly situated in a historical context and takes into account social, political, cultural and economic antecedents of the situation. This is not to suggest that quantitative approaches do not take into account the social context in which the research is carried out, however there is less emphasis on this factor.

Elliott, Fisher and Rennie's (1999) guidelines or criteria for the evaluation of qualitative research, located within the phenomenological tradition are used to demonstrate good practice. In the present studies, the researcher 'situated the sample'- describing them and their situation in as much detail as possible to assess the relevance and applicability of the findings to the context in which they were first derived. In addition, the research was grounded with examples, in other words, examples of transcripts were provided to exemplify the analytic procedures used and the understanding they generated. Good practice in qualitative research suggests that researchers should check whether their accounts are credible by referring to others' (colleagues, other researchers, participants) interpretation of the data or by applying other methods of analysis in relation to the same subject matter (Elliott et al., 1999). In both of the qualitative studies another researcher/ colleague was consulted to provide credibility checks. More importantly, investigator triangulation involved the talking through of the results of the qualitative study with a researcher from another discipline (Sociology, belonging to the Centre for Research into Ageing and Gender, University of Surrey).

There is a high degree of subjectivity in qualitative research and this is shaped by the researcher's interpretative frameworks. Good practice suggests that qualitative researchers should disclose their own assumptions to allow readers to interpret their analysis and to consider possible alternative interpretations (Elliott et al., 1999). Henwood & Pidgeon (1992) refer to this as the process of reflexivity, where the researcher's contribution to the construction of meaning is acknowledged. This can be done through a process of personal reflexivity and epistemological reflexivity. Personal reflexivity involves reflecting upon the ways in which the researcher's values, experiences, interests, beliefs, political commitments and social identity have shaped the project. Epistemological reflexivity reflects upon the assumptions (about knowledge and the world) which have implications for research and findings (Willig, 2002). Researchers studying sensitive issues suggest the importance of reflectivity in qualitative research, especially research addressing sensitive issues such as death and dying (see Owen & Payne, 1999).

In this case, the researcher was a 26 year old, female, Indian, student of health psychology. The topic was proposed by a Consultant Oncologist at the Royal Surrey County Hospital as an issue of great concern to hospital doctors and she was seeking collaborators in the Psychology Department. The researcher's interest in the area and motivation for embarking on this work was primarily an interest in the policy relevance and topical nature of the topic. The researcher's interest in health psychology in relation to older people made this a suitable topic to pursue. A detailed account of her personal reflectivity and experience of conducting focus groups is discussed in detail in Chapter 7.

4.6 Conclusion

Therefore, a mixed methodological approach was considered appropriate given the theoretical basis and the sensitive nature of the topic under investigation. Combining both qualitative and quantitative methods as way of triangulation strengthens the credibility of the research findings and increases validity by taking into account contextual factors in understanding older people's views towards advance care planning.

Chapter 5:

Older people's views on life prolongation: A content analysis

5.1 Introduction

This chapter presents the first study of the thesis. This was a pilot study conducted between May and July 2001. The study examines whether issues of death and dying, particularly life prolongation were issues relevant to older people living in the community and whether older people considered and discussed these sensitive and potentially distressing issues.

As suggested in Chapter 2, to some extent there is a taboo on discussing issues of death and dying in contemporary modern society. The medicalisation of death has resulted in a silence towards death. Therefore, individuals do not think about their mortality and prepare for their deaths, by making their wishes about life prolongation known. However, in the context of making plans for the end of life, this is particularly relevant because only when an individual contemplates death can they make adequate provision to ensure that their dying process is in accordance with their wishes. It has been postulated that older people are more likely to contemplate death and dying because of the signs of physical ageing and personal loss in the form of loved ones dying. More recently, cultural advances have broken barriers towards discussing death and dying, and there is more of a willingness to discuss these issues. However, it remains unclear whether older people in the UK living in the community wish to think about issues of life prolongation.

The research on older people's perspective towards resuscitation in the UK has been conducted on patients recruited from a medical setting (e.g. Bruce-Jones et al, 1996; Liddle et al, 1994, Mead & Turnbull, 1995, Sayers et al., 1997), with fewer studies being conducted on older people living in the community setting (e.g. Phillip & Woodward 1999; Seymour et al. 2004). Older people who are hospitalised may contemplate issues of death and dying as they are relevant to their illness context. However, older people living in the community may or may not think about issues of life prolongation. Moreover, there are concerns that participating in this research and thinking about these issues may be distressing for participants, so preliminary work prior to the main studies was essential.

Therefore, the primary aim of the study was to determine the feasibility of conducting research on advance care planning among older people living in the community setting. More specifically, the study addressed the following questions:

- What is the extent to which older people living in the community discuss life prolongation?
- What are the issues that are important to older people when thinking about their preference for life prolongation and thinking about advance care planning?
- Why do they discuss these issues?
- With whom do older people want to discuss these issues?
- What are the different ways in which they make arrangements for their care in later life?

5.2. Method

5.2.1 Meeting with experts

Prior to collecting any data, the author met with the Resuscitation Officers at the Royal Surrey County Hospital and various medical professionals (Oncologists and Geriatricians) working at the hospital. The author also attended a course on Basic Life Support supported by the Resuscitation Council. The aim of these meetings was for the researcher to learn about resuscitation and understand the medical implications and practice of these procedures.

5.2.2 Participants and Recruitment

Twelve participants (six men and six women), with a mean age of 70 years (age range of 61 to 79 years) participated in the study. There were three participants from each of the four age categories: 61-65, 66-70, 71-75, 76-80. All participants were well educated and had a strong interest in the topic of the study.

Advertisements to recruit participants for a quantitative study (chapter 6) were placed in local and national newsletters for older people and magazines read by older people. The study was described as research into decision making about health issues in the later stages of life. Interested participants living in S.E. England were given the opportunity to take part in this in-depth quantitative study. Participants spoke to the researcher on the telephone who explained the study in more detail, so that potential participants could make an informed choice about participation. Eligibility criteria were: living in the community, over the age of 60, able to understand and speak English and no evidence of dementia, delirium or depression. Participants who had a terminal/chronic condition and were not currently hospitalized were not excluded from the study. Participants who were recently bereaved were excluded.

5.2.3 Ethical considerations

In this study, data were collected from older people about sensitive issues such as death and dying. The interview topic was explained carefully to participants before they agreed to participate and they were assured that their participation was voluntary and they could end the interview session at any time. None of the participants ended the interview and none seemed unduly distressed. Follow-up contact did not suggest that participants were adversely affected by the interview. Ethical approval was obtained for this research programme from the University of Surrey Advisory Committee on Ethics, as described in Chapter 6.

5.2.4 Procedure

Participants were given an information sheet (see Appendix 1) and a consent form to sign (see Appendix 2). All the interviews were conducted either in the participant's home or at the University of Surrey. Confidentiality and anonymity was reassured and participants were given the option to terminate the interview at any time. With the permission of the participants the interviews were audiotaped and subsequently transcribed verbatim. Contact details of the researcher were provided to enable further information on any matter relating to the investigation to be easily obtained. At the end of the interview, which lasted about an hour, all participants were also provided with a list of organisations that could provide help, information, or counseling related to the issues discussed, and the researcher made a follow-up call the following day (see Appendix 4).

5.2.5 Interview

A semi-structured face-to-face interview (see Appendix 3) was conducted to explore older people's opinions about life prolongation (resuscitation and the DNAR policy) and advance care planning (discussing life prolongation with doctors and family members and / or signing living wills). The topic was introduced with questions about recent high profile legal cases (such as the recent case of Diane Pretty[1]), which were used to explore older people's interest in issues of death and dying. Probes were used to explore the values that were important while talking or making decisions about end-of-life care. During this discussion, the interviewer judged participants' knowledge about CPR and the DNAR and, if need be, explanations for these terms were provided.

Next, a series of issues were discussed in terms of older people in general, using probes as necessary to facilitate discussion. If participants were comfortable speaking about themselves and their own end-of-life care, this was encouraged. The interview schedule covered the following issues: (1) Values relevant to making decisions about end-of-life care; (2) Importance of being involved in one's own medical decisions; (3) Who should be involved in the decision making in the final stages of life and why; (4) The ease or difficulty of talking about medical care in the later stages of life with these people; (5) Planning for medical care at the later stages of life, including living wills, if the participant had mentioned them in the interview.

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[1] Diane Pretty case was a high profile case on 'dying with dignity' at the time the interviews were conducted. The 43-year-old mother of two was a sufferer of motor neurone disease and had decided that she did not want life prolongation by artificial means by ventilation or tube feeding. She was also in a case trying to win in favour of assisted suicide. Even though studying 'assisted suicide' was not part of the research agenda, it was felt that introducing the topic of Diane Pretty would help participants talk about related issues about death and dying.

Participants were finally asked what their thoughts and feeling about discussing these issues with the interviewer were and whether they found the subject distressing or stressful.

5.2.6 Method of Analysis

The transcripts from the interviews were analysed using content analysis (Weber, 1990). This approach is primarily concerned with searching for and identifying key themes present in the data, rather than confirming a set of predetermined hypotheses. Since the aim of the study was exploratory, this methodology was considered suitable. The process of content analysis involves progressive "sorts" of the data by sorting the data into categories and then re-examining the categorised data for commonalities.

The data underwent various stages of analysis. Firstly, a word or phrase that captured the meaning of the segment of text was written in the margin of the transcript. The unit of analysis (segment) could be word, phrase or paragraph that described the experience, feeling or perception reported by the participant. Secondly, the segmented text was studied by two coders (the author and another colleague) independently to generate descriptive categories and sub-categories. The themes generated were mutually exclusive (ability of the data language to make distinctions among the phenomena recorded) and exhaustive (ability of the data language to represent all recording units without exception). Thirdly, the transcripts were reanalysed using a more detailed framework, with each paragraph being coded and ascribed to one of the themes. This content analysis continued until all categories were saturated (when no new information on the characteristics of the category was forthcoming). Fourthly, reliability was ensured by the themes (independently generated by the coders) being continuously compared and discussed to determine the extent of agreement among the coders. Disagreements between the themes were discussed between the coders and themes mentioned by only one coder were not used in the analysis. An inter-rater reliability rate of 0.80 was achieved between the researcher and a colleague independently coding six randomly selected transcripts. Krippendorff (1980) suggests that reliability analysis requires at least 2 coders independently describing a large set of recorded units in terms of a common data language. Reliability was therefore expressed as a function of the agreement achieved among coders regarding the assignment of units to categories, calculated as 1 – (observed disagreement / observed disagreement (as suggested by Krippendorff, 1980). The coded texts were inspected closely to check their support for each of the themes. This allowed the researcher to keep a record of the themes that were popular and those that were less common. Finally, the frequency and percentage of participants who had mentioned a particular theme was calculated, to account for which theme was more popular than the other. The categories and themes that emerged from the analysis are described in Table 5.1.

Table: 5.1 Categories, themes and coding guide

Category	Theme	Coding guide
Factors leading older people to think about life prolongation issues	Ageing	Right time to think about death and dying. Reasons given for thinking about these issues: chronological age versus mental age and personal experience with death and dying.
	Fear of dying versus. accepting dying	Attitudes towards death: accepting death, denying death, fear of death and fear of dying
	Technology and reality of dying	Advent of medical technologies and life prolonging medical technologies
Issues/concerns when thinking and discussing life prolongation	Older person	Reasons given for thinking about life prolongation: issues important to older people when making these decisions: dignity of dying, quality of life, autonomy and ageism
	Medical Professionals	Reasons given for consulting the doctor and concerns over involving the doctor in the decision making process: ambivalence towards medical professionals, acceptance of death, medical education and truth telling
	Family	Reasons given for consulting family members and concerns over involving them in the decision making process: trusting the family, concern for the family, burden of decision making and gender differences.
Living wills as an effective means of communication		Help individuals make their minds up, issues of storage and witnessing and informing significant others.
Contextual Factors	Legislation	doctors afraid of litigation
	Religion	Coping mechanism and accepting mortality, doctors religious beliefs.

5.3 Results

Four major categories emerged from the qualitative analysis, including (1) factors leading older people to think about life prolongation issues, (2) issues/concerns when thinking and discussing life prolongation (3) living wills as a means of effective communication and (4) contextual factors. Each of these categories contained several themes, which will be reported here. A number of verbatim quotes are reported to illustrate the kind of statements that underpinned the identification of themes. In the extracts, (...) indicates that material has been omitted, material in brackets ( ) was added for clarification by the authors, and the age and sex of the participant is presented with each of the quotes.

5.3.1 Factors leading older people to think about life prolongation issues

The concept of the 'right time' was an important determinant of thinking about and making decisions on life prolongation. More importantly, were these issues that non hospitalised healthy older people contemplated? Three themes emerged: 'ageing'; 'fear vs. acceptance of dying' and 'technology and reality of dying'. The summary table of the frequency of accounts is presented here (Table 5.2).

Table 5.2: Participants' accounts of when they think about and make decisions on life prolongation (n = 12)

Accounts	Frequencies (%) Yes	Frequencies (%) No
Ageing	11 (91.67 %)	1 (8.33 %)
Fear of Dying VS Accepting Dying	8 (66.67 %)	4 (33.33%)
Technology and reality of dying.	4 (33.33 %)	8 (66. 67 %)

5.3.1.1 Ageing

The majority of the participants (11 out of 12) talked about ageing acting as a reminder for them to think about life prolongation. Participants who did not think of themselves as old were less likely to think about these issues.

> *'Don't think about it (death), because I don't feel old and hence it not a time for me to consider these issues. My parents lived till they were 90, so I guess I have about 30 odd years left'* (Woman, 60 years)

Some participants acknowledged that it was not only chronological age but rather mental age, which was an indicator of being 'old'.

> *'To talk about these issues one needed to feel old as well.'* (Woman, 65)

However, others suggested that age or rather chronological age was not the only factor to consider when evaluating the 'right time' to think about life prolongation. Participants accepted that decisions in this area should not be made or thought about when the individual was too young, but equally it was important not to delay till the patient was too ill to make the decision for themselves.

> *'I don't feel old enough as yet. Yet I don't want to wait till the day before I go into hospital before having the conversation about my wishes, if I was no longer able to make them myself. It is all about timing...it is the question of getting the timing right ... of not wanting to discuss it because I do not feel old enough and also not waiting till I am too old and too ill to talk to them about my wishes.'* (Woman, 76 years)

A participant did not consider age but good health as a prerequisite to making arrangements for care in the later stages of life.

> *'I think it is important to discuss end-of-life issues with one's doctor while still in good health, regardless of age, when discussions can be more objective, without the emotional factors that may colour one's judgement when faced with the prospect of death'* (Man, 72 years)

The experience of aging also involves losing loved ones and loved ones or themselves being terminally ill. Such experiences made older people think about their own mortality and also in some cases made it easier to discuss these issues openly in the family setting. Five participants indicated that losing a friend or close family member or being ill themselves led to communicating about death and dying with family members.

> *'Having cancer has been a hard experience for all of us (referring to self and family) but it made me realize that I may not be alive forever. This has got me thinking that I want to die with dignity, the way I lived my life. I*

> *have made sure that I have given this (life prolongation) some thought and spoken to my family about my wishes.'* (Man, 72 years)

5.3.1.2 Fear versus acceptance of dying

Eight of the 12 participants mentioned fear of dying and acceptance of dying as being an important determinant of contemplating the relevance of life prolongation. Older people believed that accepting the inevitability of death made a person more likely to think about these issues as compared to someone who was in denial about their own mortality.

> *'There is a time to live and a time to die, we are not immortal... and accepting it is important, as people who accept the inevitable will be able to talk about it'* (Man, 78 years).

The experiences associated with ageing may lead older people to contemplate their own mortality resulting in thoughts about their care in later life. However, not all had an accepting attitude towards death and dying and this was often combined with a fear of death and dying.

> *"It is the one thing in the world that will happen to everybody, there is no exception whether you are Osama Bin Laden or Tony Blair, whoever you are ... you cannot escape it. And the weird thing is that it is the one thing that we all fear the most..."* (Woman, 68 years).

> *'I do not fear being dead, it is the going that I have my reservations on.'* (Man, 71 years).

A plausible explanation suggested for the inherent fear of dying, as suggested by one participant:

> *'It's the feeling of not knowing what the family will be doing, knowing that you will be leaving things behind, the feeling of not knowing what my son will be doing or being able to look after my grandchildren.'* (Woman, 68 years).

Some participants did not think about death and dying and were less likely to think about life prolongation.

> *'I am not sure I am ready to think about myself in a coffin'* (Woman, 62 years).

5.3.1.3 Technology and reality of dying

Four participants raised the need for people to discuss end-of-life issues because of the advent of medical technology that can prolong person's life. At a time when medical advances can defer death, denying the reality of death becomes difficult.

> *'With science advancing so rapidly, these issues must be thought about. In the past, they did not have these issues to think about and hence it was easier to deny the reality of death'* (Woman, 70 years).
>
> *'It was difficult in my grandmothers time, when these issues could not be spoken about, trends are changing, now people are more likely to talk about these issues.'* (Woman 68 years)

In sum, responses indicated that the 'right time' or 'when' was when the person felt old enough but not too ill and when the older person accepted the reality of dying and/or they had a personal experience with death and illness. Further, in an age of medical advances it was seen as important to discuss these issues.

5.3.2 Issues/concerns when thinking and discussing life prolongation

The decision to prolong life is not made in isolation and involved medical professionals and family members. Hence a discussion is warranted before making decisions and often a discussion informing significant others, such as doctors and family members about their decision is also required.

The discussion about 'with whom' included comments on the issues and concerns for the older person themselves, the doctor, and the family.

5.3.2.1 Older Person

Participants in the study wished to make the resuscitation decision themselves and had various issues and concerns which they would take into account while contemplating resuscitation decisions. These included: 'dignity of dying'; 'quality of life'; 'autonomy' and 'ageism'. See Table 5.3 for a summary of frequencies of older people's account of issues and concerns that are important to them when they make decisions on life prolongation.

Table 5.3: Participants accounts of the issues and concerns they had about themselves being involved in decisions on life prolongation (n = 12)

Accounts	**Frequencies (%)**	**Frequencies (%)**
	Yes	**No**
Dignity of Dying	10 (83.33 %)	2 (16.67 %)
Quality of Life	9 (75 %)	3 (25 %)
Autonomy	8 (66.67 %)	4 (33.33 %)
Ageism	3 (25 %)	9 (75 %)

Dignity of dying. A majority of participants (10 out of 12) wished to die with dignity, and this was an important determinant when considering decisions on life prolongation.

> *'Just as we put a dog down to stop them for suffering anymore and let them die with dignity, why don't we do the same with people?'* (Woman, 62 years)

Having a natural, peaceful death, where they are cognitively able till the end was considered a dignified death. Some participants spoke about being opposed to a medicalised death and wishing to die with some dignity. The major concern was to be remembered as a dignified person not only in life, but also in death.

> *'I don't want to die with machines attached to every part of my body, where I am not able to say my goodbyes and not able to be remembered as a dignified person'* (Woman, 70 years)

> *'Well, I think that everyone would like to have a dignified death... I want to be remembered with dignity, calmly, and leave the people I love and care about when they can remember me as a sane person.'* (Man, 63 years)

Therefore, a technological death with the use of life prolonging medical technologies was considered undignified.

> *'I fear more than anything else a painful, prolonged and undignified process of dying'.* (Woman, 70 years).

Quality of life. Nine out of 12 participants suggested that quality of life was important to them while making decisions on life prolongation. Participants agreed that decisions should be based on the quality of life of the individual or a *'life worth living'* (Woman, 70 years) and they did not want to live in *'... a vegetative state'* (female, 62) or in a *'...cabbage-like existence'* (Man, 78 years).

Older people suggested that it was important to inform or communicate their wishes of an acceptable quality of life to their significant others (namely doctors and family) so that decisions on life prolongation, when they were incapable of making them, would take into account their accepted quality of life.

> *'My family and doctors know my views on a quality of life acceptable to me, and will respect my wishes if I happen to be under their care terminally.'* (Woman, 68 years).

Autonomy. A large proportion of participants (8 out of the 12) wanted to have autonomy or control in their decision making. This would enable them to ensure that their dying process was in accordance with their wishes.

> *'The way I see it, is that we had no control in our birth process and hence it is important for me to have control over the death process. I want to be able to make sure that I die in a suitable way, which is consistent with the way I lived my life ... making my own decisions and being aware of things. I don't think that is an unrealistic expectation'* (Man, 76 years).
>
> *'If I can't make my own decisions...I do not think my life is worth living'* (Woman, 70 years).

Ageism. A smaller minority of participants (3 out of 12) commented on ageism within the health system, where older people feared under-treatment (or the non use of CPR) because of their advancing age and the view that they were a burden to society.

> *"I think that there is a problem ...because there is the myth about old people that the they are a burden to society and I personally think that doctors may put a DNR on a older person's file only because of this reason"* (Man, 63 years).

5.3.2.2 Medical Professionals

Medical professional's involvement in the resuscitation decision was seen as imperative as this was essentially a medical decision and they were viewed as most equipped to offer advice on the efficacy of treatment. However, participants voiced concerns about involving doctors in the decision making process: 'ambivalence towards medical professionals; 'acceptance of death'; 'medical education'and 'truth-telling'.

Table 5.4: Participants' accounts of the issues and concerns when involved medical professionals in decisions on life prolongation (n = 12)

Accounts	**Frequencies (%) Yes**	**Frequencies (%) No**
Ambivalence towards medical professionals	7 (58.33 %)	5 (41.67 %)
Acceptance of Death	4 (33.33 %)	8 (66.67 %)
Medical education	3 (25 %)	9 (75 %)
Truth telling	2 (16.67 %)	10 (83.33 %)

Ambivalence towards medical professionals. Seven out of twelve, participants viewed doctors with a degree of ambivalence. They acknowledged that medical professionals were the most appropriate for a clinical diagnosis, but doctors were seen as difficult people to discuss these sensitive issues with. One of the main reasons cited for not involving doctors was that they did not know about the older people's values and these were not taken into account when making decisions on life prolongation.

> *'No! Doctors are not anyone to speak to...I know that they may be the most skilled to give the right medical decision...but they don't know me ...they don't know my values and they are the most uninterested people'.* (Woman, 60 years)

Acceptance of death. Four out of twelve participants felt that doctors do not accept death as a reality and hence were unable to discuss these sensitive issues with their older patients.

> *'The problem, I believe that when doctors and medical professionals are unable to discuss death and end of life care it is because they themselves have not come to terms with the reality of death themselves.'* (Man, 73 years)

It was suggested that doctors were more biased towards resuscitation because they were unable to accept death.

> *'Medical professionals may have unresolved issues (towards death) of their own and who can't come to terms with them. This situation is sometimes reflected in the inappropriate late-stage treatment applied to their ill patients, these being mirror image of the professional's personal attitudes towards death'.* (Woman, 60 years)

Medical education. Medical education (Western Medicine), with the emphasis on cure and view that death is a failure was another reason cited by participants (n = 3) that made it difficult for doctors to talk about end-of-life issues with their patients.

> *'The scientific based training of the medical professionals tend to encourage the driving towards ultimate solutions and the death of a patient is often looked upon as a failure. This is one of the problems of scientifically based medicine.'* (Man, 79 years).

Truth telling. Another plausible explanation provided by participants for doctors failing to talk with their older patients about end-of-life issues is that medical professionals do not want to upset their patients when delivering bad news and are wary of risking more psychological damage to the patient.

> *'People who deliver bad news must be careful not to upset the patient and cause more damage. I think that this is a big responsibility on medical professionals and this is perhaps why they are unable to talk about EOL care'* (Woman, 73 years).

5.3.2.3 Family

Most participants would rather their family was involved in the resuscitation decision than the doctor. One of the main reasons for choosing the family over medical professionals in the resuscitation decision was issues of trust. However, consulting family members in the decision included various issues and concerns including: 'burden of decision making'; 'concern for the family' and 'gender differences'.

Table 5.5: Participants' accounts of the issues and concerns when involving family members' in decisions on life prolongation (n = 12)

Accounts	**Frequencies (%)** **Yes**	**Frequencies (%)** **No**
Trust family	5 (41.67 %)	7 (58.33 %)
Burden of decision making	10 (83.33 %)	2 (16.67 %)
Gender differences	3 (25 %)	9 (75 %)

Trusting the family. One of the main reasons for involving family members or choosing them over medical professionals was that older people trusted them more to ensure that their dying process was in accordance with their wishes. Family members know their older relative and decisions on quality of life would hence be easier to make.

> *'My doctor does not know me. In the past 2 years I have changed 3 GP's and I have no relationship with the doctor. If I ever go into hospital I will be under the care of medical professionals that I don't know. I want my family to make the decisions for me. They are the one's that know me, they are the one's that will make sure than my medical treatments is in accordance to my wishes and is consistent to the way I have lived my life... with dignity. I want to die the same way and I trust my family to ensure that this happens.'* (Woman, 70 years).

However, other participants suggested that this should be a joint decision between the doctor and the family. The doctor's involvement reflected clinical expertise, while family members' involvement was justified by knowing what the patient wanted.

> *'At the moment I am capable of making decisions on my own, but if not I want my family involved. The doctor will give the initial clinical diagnosis, but the family members need to be taken into account. They know me, they know what I want, not the doctor'* (Woman, 62 years).

Some participants wanted the family involved in the decision making but to a lesser extent, where they would have no real decision making powers and consulting them was a mere obligation.

> *'Relatives should not be involved, 'cause this a medical decision, however they should be consulted and they should agree with the decision'* (Woman, 60 years)

Burden of decision making. Older people envisaged that decisions on life prolongation would be burdensome to the family. However, they thought these hard decisions would become easier when communication has occurred and this would help family members cope with the loss and grief.

> *'It is such a burden for the family to make the decision, should they advise the doctor to resuscitate or not, they have to live with it afterwards and not knowing what the person wanted could be a very hard decision. Unless you make it known to them before hand.'* (Man, 73 years).

Some felt that family members may be incapable of making decisions at the end of life because they may be too emotional about losing their ageing relative and hence may not be rational about their choice.

> *'Family members may be laden with guilt or be too emotionally attached to make the right decision.'* (Woman, 62 years).

Further, concerns of burden also had an effect on older people's choice for life prolongation. It was envisaged that prolonging their own lives, especially without quality of life would be burdensome and stressful for family members.

> *'Terrible to prolong life especially for the family. The person involved does not know better.'* (Woman, 62 years).

> *'If there is a choice between my family suffering because I was prolonging my life unnecessarily and me, the patient suffering because of recovery. My concern for the family will come first... 'cause I will not know the better and they will suffer more.'* (Man, 76 years)

Gender differences. Participants tended to view their female family members as more supportive and found it easier to talk about end-of-life issues with them rather than the male members of their family. They tended to attribute this gender difference to the social norm that woman were more comfortable than men at discussing sensitive and emotional matters.

> *'My son finds the idea of me dying very troublesome, and does not like to talk about it unlike my daughters who are very supportive of my wishes. In theory my son has agreed to make sure my wishes are respected...but I know how difficult he finds it to talk ... he is a man and that's the way men are.'* (Woman, 68 years).

5.3.3 Living wills as an effective means of communication

Living wills (or advance directives) were spontaneously mentioned by a large proportion of the participants.

Table 5.6: Participants' accounts of living wills (n = 12)

Accounts	**Frequencies (%)** **Yes**	**Frequencies (%)** **No**
Living wills as an effective means of communication	9 (75 %)	3 (25 %)

Living wills were positively regarded as an important tool and an effective means of communication. These help individuals contemplating these issues to make up their minds about their preferences for life prolongation. The mechanisms involved in storing and witnessing a living will help older people communicate their preferences to their doctors and family members.

> *'It is good for people who make up their minds and can be used as an important tool.'* (Woman, 62 years).

> *'It gives people some sort of assurance and a degree of certainty that their wishes will be respected... not because of the legal backing but because witnessing and storing requires that you speak to your doctor and family members about your wishes.'* (Woman, 68 years).

Interestingly, only 2 out of the 9 participants who endorsed the benefits of advance directives had signed a living will.

5.3.4 Contextual factors

Life prolongation decisions and communication of preference takes place under the backdrop of contextual factors, such as legislative and organizational factors that exist in society and the context of religious values.

Table 5.7: Participants' accounts of contextual factors affecting resuscitation decisions (n = 12)

Accounts	Frequencies (%) Yes	Frequencies (%) No
Legislation	5 (41.67 %)	7 (58.33 %)
Religion	6 (50 %)	6 (50 %)

5.3.4.1 Legislation

Participants attributed medical professionals' lack of communication about end-of-life care to the legal mechanisms that exist in contemporary society.

> *'I feel reluctance on the part of medics and paramedics to discuss end of life issues because of the ambivalence in the law. I see it as a head in the sand situation for them and many of them may feel threatened by the potential changes in the law.'* (Man, 73 years).

5.3.4.2 Religion

Participants viewed religion as either a coping mechanism or as a contextual factor while discussing end-of-life issues.

> *'I don't look at death as an end...I think a lot of religions have it right. Being religious has helped me cope with accepting that this will eventually happen and I will move on to another place.'* (Woman, 62 years).

Doctors' religious orientation also influenced older peoples' belief in their ability to communicate effectively with their patients.

> *'I believe my doctor to be Roman Catholic and they tend to support the prolongation of life... Suffering ennobles the spirit.'* (Woman, 68 years).

5.4. Summary and discussion

As a small-scale qualitative study, this research has proved valuable in identifying important issues to explore more extensively. Older people living in the community discussed life prolongation and advance care planning with ease and considered these issues as personally relevant. Despite earlier reservations about healthy older people's willingness to participate in the study and discuss these sensitive issues with the researcher, participants discussed these issues with relative ease, often demonstrating that these issues had been previously thought about. Ageing and the experiences associated with growing old reminded older people of their own mortality and encouraged them to contemplate the care they would like at the later stages of life and discuss these issues with their significant others. Concerns were expressed about getting the timing of advance care planning right, with a risk of waiting until one is too ill or close to death, which may affect one's judgment when faced with the prospect of death. Therefore, older people agreed that advance care planning should not be postponed till the patient is seriously ill or hospitalised but rather be conducted earlier.

In general, the findings of the study suggest that older people who accepted their own mortality were more likely to think about and discuss end of life issues. However, others who denied the inevitability of their own death did not wish to discuss these issues. Social cognitive models, particularly the TPB suggests that an attitude towards the behaviour has an effect on whether individuals intend to perform the behaviour. Interestingly this study suggests that thoughts about death and dying rather than attitudes towards life prolongation and/or advance care planning have an effect on whether older people wish to make decisions on life prolongation and/or conduct advance care planning. This finding is important as it indicates that perhaps positive or accepting attitudes towards death and dying is a prerequisite to contemplating about these issues.

The aim of this study was to investigate the issues that were salient to older people when thinking about their preference for life prolongation and thinking about advance care planning. The results indicate that older people wish to talk about their medical care in the later stages of life, because dying with dignity, maximising quality of life and having autonomy and control over their dying process was important to them. These older people were fearful that there was ageism in the healthcare system. Preference to preserve a good quality of life is associated with preference regarding life prolongation and description of an adequate quality of life are used by older people when communicating their intentions to doctors and family members (e.g. Ebell et al., 1990; Phillips & Woodward, 1999; Singer et al. 1999). Older people in the study regarded autonomy or control in the decision making process as important. This is consistent with past research suggesting the ability to enact self-control over one's life is vital to individuals who conduct advance care planning (Collopy, 1990; Eisemann & Richter, 1999; Kelner et al., 1993; Hoflin, 1988). It is not surprising that the sample in this study, particularly as they were more educated and of a higher socio-economic status, valued autonomy or control in the decision making process. Previous research has suggested that the desire for control is associated with socioeconomic characteristics such as education and having held more professional and managerial jobs (Kelner, 1995). The desire for control or autonomy in decisions regarding life prolongation is similar to the concept of perceived behavioural control. Therefore an individual wishing to enact behaviour (advance care planning) should feel that they have the ability or control to influence the course of action.

Consistent with past research, older people indicated that they wished to talk to their doctors and family members about their end-of-life issues (e.g. Frank et al., 2003; Seymour et al., 2004). However, their concerns about talking to medical professionals included ambivalence towards doctors and concerns over medical education and lack of professional standards in the medical profession. Further, older people maintained that doctors needed to accept the reality of death to be able to communicate end-of-life issues with their patients. Older people wish to include physicians as they were regarded as an authority in the field of resuscitation based on their expertise in prognostication and treatment (Rosenfeld et al, 2000). However, the findings of this study suggest that there is ambivalence towards medical professionals while involving them in decisions of life and death. It was acknowledged that medical professionals may know the best medical prognosis but were less likely to know the older person's personal values and preferences when making these complex decisions.

Previous research on medical professional's failure to initiate resuscitation discussion have suggested that there is a lack appropriate communication skills, since there is little formal training provided to discuss issues of death and dying, their own fear of death prevents them facing the death of their patients and their own discomfort with the topics makes them avoid discussion on death and dying (e.g Marik & Zaloga, 2001). Interestingly, older people seem to have similar views and therefore had concerns about involving their doctors in discussions about resuscitation. Further, research on medical professionals suggests that they do not want to cause emotional pain or be the bearer of bad news and doctors think that by discussing these issues it may endanger the patient's health and life (e.g. Johnson et al., 1993, 1998). Older people in this study acknowledged the collusion (news of a poor prognosis is kept from a patient) takes place at the time of hospitalisation and at the time of serious illness. Older people were in agreement that the time of the discussion was perhaps the reason why doctors were unable to discuss life prolongation with their patients.

Additionally, older people also wished to talk to their family members, as these were the individuals who really knew them and would ensure that their medical treatment was in accordance with their values. However, results indicated that older people were concerned about the families' involvement in making these decisions. The older person regarded these decisions as being hard for the family to make and potentially a burden. This finding is consistent with previous research on terminally ill patients who wish to exclude their family members in life prolongation decisions to relieve feeling of guilt and not be a burden on caregivers (Aikman et al., 1999; Singer et al., 1998). Seymour et al. (2004) in their study of older people living in the community in the UK reported that older people recognised that putting the trust of decision making on the family was surrounded by risk and a 'dauntingly heavy responsibility' (p.62). This perceived burden could be contained by signing living wills. With respect to family involvement in life-prolongation decisions, older people in this study perceived that families assume responsibility and were automatically asked to make decisions for them in the case of incapacitation. This poses several important implications for decisions on resuscitation which are essentially medically dominated (as discussed in chapter 2).

These results suggest that the older person's views of what their significant others, namely their doctors and family members thought about these issues, affected their intention to conduct advance care planning. These become particularly relevant because advance care planning involved the cooperation of medical professionals and family members in either providing information or in executing the preference when the older person is incapacitated. Therefore, it is hardly surprising that the views of these significant others towards resuscitation and advance care planning affected older people's intentions to perform the behaviour in question. These subjective norms that older people regarded as salient when contemplating life prolongation and advance care planning also encompassed contextual factors such as legislation and religion.

Although not explicitly mentioned by participants, the media was another contextual factor which influenced older people's views on resuscitation and advance care planning. During the time in which the interviews were conducted, two particular media sensations perhaps had an influence on older people's perceptions on these issues. Firstly, Diane Pretty's case on 'dying with dignity' - a 43-year-old mother of two was a sufferer of motor neurone disease and had decided that she did not want life prolongation by artificial means by ventilation or tube feeding. The participants in this study mentioned that dying with dignity is an important value when making decisions about life prolongation, suggesting that they were influenced by the media coverage. Secondly, there was much media attention of ageism in the resuscitation decision and concerns that despite BMA recommends clinicians failed to discuss life prolongation with their older patients and concerns that DNAR was written in older people's notes without their knowledge. Perhaps the media coverage on ageism within the National

Health Service (NHS) make older people believe that advanced age would result in under treatment and age was used as criteria for making resuscitation decisions by medical professionals.

A large proportion of participants in the study suggested that they were aware of living wills and demonstrated an adequate level of knowledge regarding its usefulness. However, previous studies in the UK have suggested that older inpatients had inadequate knowledge about advance directives (e.g. Schiff et al., 2000; Seymour et al., 2004). Despite the large proportion of the sample knowing about living wills, few had signed one.

This small pilot interview study suggested that older people living in the community found issues of life prolongation and end-of-life decision making as personally relevant and were willing and comfortable discussing these sensitive issues. Although a small and unrepresentative group of participants, they raised some interesting themes (such as dying with dignity, quality of life, rights of autonomy and safeguarding against ageism were important factors they considered when thinking about resuscitation decisions). These themes were used to inform and expand the Theory of Planned Behaviour (TPB) which was used in the next empirical study (see Chapter 6). The findings of this study confirmed that the TPB might prove useful as the underlying theoretical model. For example, the content analysis suggested that positive attitudes towards death and dying appeared to influence participants to contemplate conducting advance care planning. The importance given to families, religion and legislation, suggested that TPB's variable of subjective norms would predict advance care planning. Living wills were viewed as a way of ensuring that the dying process was in accordance with their wishes, whereas involving the doctor was viewed with ambivalence, because of the heavy 'pro-life' emphasis within medical circles. Therefore, it appeared that issues of control were also considered in making decisions regarding advance care planning.

This study had some inherent limitations. The sample size was very small and this self-selecting sample were very interested and well informed about life prolongation and related issues. The sample was recruited from Guildford, a relatively high socio-economic background and highly educated background. Future work should include a wider range of participants, including, those with a lower socio-economic status, older people who are not so well versed with advance care planning and perhaps those with different attitudes towards discussing death and dying.

5.5 Conclusions

Therefore, this initial study indicated that end-of-life decision making was relevant to older people living in the community and discussing these issues with them was feasible. Secondly, the findings provided some degree of preliminary support for using TPB as a theoretical model. Finally, the findings of this study were used to inform and expand on the next study.

Chapter 6:

Using the Theory of Planned Behaviour to predict intentions and behaviour regarding advance care planning: A longitudinal quantitative study

6.1 Introduction

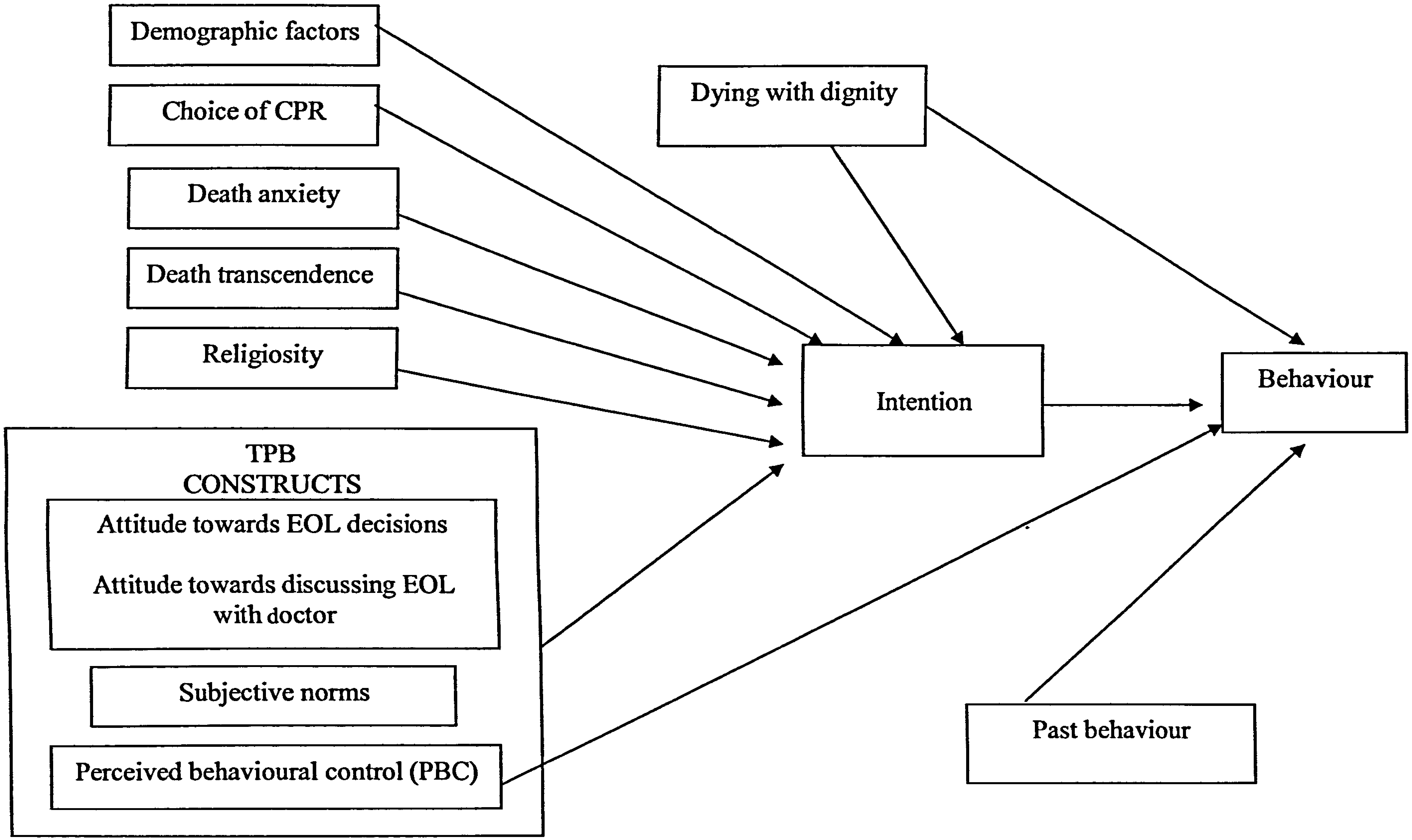
The present study had two broad aims. The first was to examine descriptive data about older people's knowledge regarding advance care planning. The second was to test the Theory of Planned Behaviour (TPB) and explore the role of additional psychological constructs in predicting whether older people conduct advance care planning. The behaviours under consideration were discussing end-of-life issues with their doctors and signing living wills (or advance directives). The additional predictors included values regarding dying with dignity. These values are important to older people when making decisions about whether they wish to discuss end-of-life issues with their doctors and/or sign living wills, and they were identified in the pilot interviews, reported in Chapter 5. In addition, three further variables considered of potential relevance were examined as possible predictors of older people's wishes to conduct advance care planning. These were death anxiety (individuals' attitudes towards death related issues), death transcendence (how individuals wish to be remembered after they die) and religiosity.

This study used a longitudinal design with a six month follow up. At Time 1, older people's intentions to discuss end-of-life issues with their doctors and their intentions to sign a living will were explored. Six months later at Time 2, their corresponding behaviour was assessed and predicted using Time 1 variables.

6.2 Model and hypothesis

Based on the TPB, empirical study 1 (Chapter 5) and the past literature (reported in chapter 3), a model hypothesising the relationships between psychological variables and intentions and behaviour was developed (see Figure 6.1).

Figure 6.1: Predicting intentions at Time 1 and behaviour at Time 2



The present study investigated the cross-sectional relationships at Time 1 among socio-demographic variables, TPB constructs, other psychological constructs and intentions (as shown in Figure 6.1). The model proposes that demographic variables, positive attitudes towards end-of-life care, positive attitudes towards discussing end-of-life issues with doctors, higher subjective norms and more perceived behavioural control regarding discussion with doctors, will lead to stronger intentions to discuss end-of-life issues with doctors. Further, those who value dying with dignity when making decisions on resuscitation, are expected to be more likely to want to discuss these issues with their doctors. In addition, it was hypothesised that older people not wishing to be resuscitated would have stronger intentions to discuss these issues with their doctors.

Older people have lower levels of death anxiety than middle aged people and these lower levels of death anxiety are associated with higher religiosity (e.g. Tomer, 2000). Healthy older people move towards a greater acceptance of the past and as a consequence accept their mortality, therefore it has been postulated that death anxiety would be lower (see Fortner, Neimeyer & Rybarcyk, 2000). Therefore, it was hypothesised that lower death anxiety would be related to higher intentions and higher death transcendence would be related to higher intentions. It was also hypothesised that lower religiosity would result in higher intentions to discuss end-of-life issues with their doctors.

Similarly, intentions to sign a living will would be predicted by demographic variables, attitudes towards end-of-life care, subjective norms and more perceived behavioural control over signing a living will. Further, more value on dying with dignity, less death anxiety, more death transcendence and less religiosity would predict intentions to sign a living will. Again it was hypothesised that older people not wishing to be resuscitated would have stronger intentions to sign a living will.

At follow up, at Time 2, intentions and PBC were used to predict whether older people had discussed end-of-life issues with their doctors. In addition it was hypothesised that dying with dignity would have a direct effect on discussing end-of-life issues with doctors. The role of past behaviour (discussed end-of-life issues with doctors at Time 1) on predicting future behaviour (discussed at Time 2) was explored. The intention-behaviour gap was examined by assessing practical barriers.

Similarly, at follow up, at Time 2, intentions and PBC were used to predict whether participants had signed living wills. In addition it was hypothesised that dying with dignity has a direct effect on signing a living will. The role of past behaviour (signed living will at Time 1) on future behaviour (signed living will at Time 2) was explored. The intention-behaviour gap for signing a living will was examined by assessing practical barriers.

In summary, the present study explored the predictive validity of the TPB in predicting intentions and behaviour to discuss end-of-life issues with doctors and/or sign living wills. As observed earlier (Chapter 2), this is a relatively new area for research and hence this study aimed to provide descriptive data and to begin some exploratory model testing. The following research questions were posed.

6.3 Research questions

At time 1,

1) Various exploratory, descriptive research questions were addressed.
- What is the prevalence of knowledge about CPR?
- Do perceptions of success rates of CPR influence choice of CPR?
- Do older people prefer to discuss end-of-life issues with their doctors or family members?
- What is the prevalence of knowledge about living wills?

2) Can intentions to discuss end-of-life issues with doctors be predicted from demographic variables, TPB constructs and other psychological predictors? Do other psychological variables such as dying with dignity, death anxiety, religiosity and death transcendence add to the prediction of these intentions? Does choice of life prolongation have an effect on intentions to discuss these issues with doctors?

3) Can intentions to sign a living will be predicted from demographic variables, TPB constructs, and other psychological variables? Do other psychological variables such as dying with dignity, death anxiety, religiosity and death transcendence add to the prediction of these intentions? Does choice of life prolongation have an effect on intentions to sign a living will?

At Time 2,

4) Do intentions to discuss end-of-life issues with doctors and perceived behavioural control at Time 1, and dying with dignity predict whether older people discuss end-of-life issues with their doctor?
5) Does past behaviour (discussed end-of-life issues with doctors at Time 1) predict future behaviour (discussed end-of-life issues with doctors at Time 2)?
6) Do participants who intend to discuss these issues with their doctors, do so? In other words, is there a gap between intentions and behaviour?
7) What are the practical barriers that may influence individuals who had intended to discuss end-of-life issues and had not performed the behaviour?
8) Similarly, do intentions to sign a living will and perceived behavioural control and dying with dignity predict whether older people sign a living will?
9) Does past behaviour (signed living will at Time 1) predict future behaviour (signed living will at Time 2)?
10) Do participants who intend to sign living wills, do so? In other words, is there a gap between intentions and behaviour?
11) What are the practical barriers that may influence individual's who had intended to sign a living will and not done so?

6.4 Method

6.4.1 Participants and Recruitment

Advertisements to recruit participants were placed in local (University of Third Age, University of Surrey, Surrey Advertiser) and national (Old Feminist Network, Voluntary Euthanasia Society, Oldie magazine, Greater London's Pensioners' Society) newsletters and magazines read by older people. In addition, various day care centres and lunch clubs were approached in Surrey, where adverts were put up on notice boards for prospective participants to contact the researcher. In some cases a day was arranged for the researcher to go to the day centre and distribute questionnaires to interested participants and address any questions or queries. Further, the Centre for Research into Ageing and Gender (CRAG) at the University of Surrey contacted older people in their database by writing to them about the study. Interested participants directly contacted the researcher.

The advert (see copy in Appendix 5) described the study as research into personal autonomy and the degree to which older people want to participate in medical decision making in the later stages of life. Interested participants were given the opportunity to contact the researcher, who spoke to them on the telephone or in person, explaining the aims of the study and assessing eligibility. At this stage, participants were told that the study was investigating older people's views about their medical care during the final stages of life. Further, participants were told that these were important issues to consider since medical advances can now keep people physically alive, sometimes without talking with the patient about their preferences. It was explained that the researchers were particularly interested in studying older people who are not in hospital because this was a good time for people to think and make decisions about the kind of care they would like to receive. Participants were informed that the aim of the study was to find out how we can help people have good discussions with their doctors, nurses and family members about these difficult issues. Participants were informed that they would be asked to complete a questionnaire on their knowledge of life-prolonging measures such as resuscitation, and the degree to which they would like to discuss these issues with their doctors, family members and sign living wills.

Eligibility criteria were: living in the community, over the age of 60, able to understand and speak English and no evidence of dementia, delirium or depression. Participants who had a chronic illness such as cancer but were not currently hospitalised were not excluded from the study. Participants who were recently bereaved were excluded. Participants were informed that all information provided would be treated in the strictest confidence. The study was approved by the University of Surrey's Advisory Committee on Ethics.

6.4.2 Measures

6.4.2.1 Time 1 questionnaire

Demographic information

The questionnaire (See Appendix 7) assessed demographic variables including age, gender, religion, ethnicity, level of education, marital status, annual income, occupational status and present health status (see items 1-13). Participants were asked to indicate their age, selecting from age range categories of 60-69, 70-79, 80-89, 90+.

Beliefs about medical professionals and family members involvement in end-of-life care

Participants were asked to rank order from 1 to 8, using 1 for the most likely person and 8 for the least likely person, with whom they would discuss end-of-life issues (item 16), choosing from spouse, children, siblings, friends, religious head/clergy, nurse, other medical professionals and their doctor.

Participants were asked to indicate their agreement with the following statements: 'I trust doctors to make the right decision about my medical care, if I were terminally ill or in a coma' (item 24), 'I want to talk to my doctor about the options for end-of-life care' (item 28), 'I feel that discussing end-of-life issues with my doctor is irrelevant at this point in my life' (item 33), 'I feel the need to discuss end-of-life issues with my doctor' (item 34), 'I am uncomfortable talking to my doctor about end-of-life care' (item 30) and 'I would only want to talk to my doctor about end-of-life care if I was terminally ill' (item 31). Participants were also asked these questions about their feelings about family members' involvement in end-of-life decision making (items 37, 41, 47, 48, 44). Items were measured on a 4-point response scale ranging from 1 = 'strongly agree' to 4 = 'strongly disagree'. These items were analysed individually.

Cardiopulmonary Resuscitation (CPR)

Participants were given a short explanation about CPR and the DNAR. "On admission to hospital, a full medical assessment of each patient is made. Doctors decide which treatment is appropriate for each patient. Doctors also decide whether or not to *resuscitate* a patient if he or she has a *cardiac arrest.* The medical practitioner is meant to discuss this with you before reaching a decision about resuscitation. 'Cardiac arrest' means that a patient's heart and lungs suddenly stop working and the patient collapses and becomes unconscious. 'Resuscitation' involves doctors and nurses pumping on a patient's chest (known as CPR: Cardiopulmonary Resuscitation), putting him or her on a drip, and if necessarily on a breathing machine. A small electric shock applied across the heart and lungs may also be needed. The aim is to restart the heart and lungs and revive the patient. Doctors can also make decisions *not to resuscitate* a patient, by putting a DNAR (Do-Not-Attempt to Resuscitate) order on the patient's files. This ensures that resuscitation will not be initiated." (See section 6 of the questionnaire, Appendix 7). Participants were asked if they had heard of CPR prior to reading this paragraph (item 79), and responded by 'Yes' or 'No'. If they answered 'Yes' to the question, they were asked where they had had first heard about CPR, by circling one of the following: your GP, in the hospital, television, radio, books/magazines, family member, lawyers or others (item 80). Participants were also asked about whether they had previously heard of the Do-not-attempt to resuscitate (DNAR) order (item 81), whether they had discussed it with their doctors (item 83), and given a choice would they like their life prolonged by CPR in the event of a cardiac arrest (item 84), and whether they had been resuscitated (item 82). The response options to these questions were 'Yes', 'No' and 'Don't know'. Participants estimated the success rate of CPR. Success was defined as 'a person's heart and lungs start working independently again. 10 % means that 10 people in 100, 90% means 90 people in 100'. Response options were: 'less than 10 %, 10-20 %, 20-30 %, 30-50 %, 50-70 %, 70-80 %, 80-90 %, and 90 % & more' (item 85).

Values important when making end-of-life decisions

Participants were asked whether they 'want to be treated with dignity when they can not longer can speak for themselves' (item 51), 'do not want to be a burden on their families' (item 52), 'want to experience a comfortable dying process' (item 53), 'want to make my own decisions regarding my death' (item 54) and 'want to be treated in accordance with my own religious beliefs' (item 55). Items were measured on a 4-point response scale ranging from 1 = 'strongly agree' to 4 = 'strongly disagree'. Principle- component analysis followed by oblique rotation on the five items resulted in only one factor with an eigenvalue greater than 1. The factor accounted for 63.80 % of the variance suggesting that these items formed one factor labeled 'Dying with dignity'. For analysis the mean of the five items was used. The internal consistency of the scale was somewhat low but acceptable for a brief scale (alpha = .65). A Cronbach coefficient alpha of .70 or greater is considered an indicator of good internal reliability (Kline, 1993). The internal reliability of the dying with dignity scale was moderate, indicating that the results using this scale should be interpreted with caution.

Discussing end-of-life issues with doctors

The questionnaire also contained several items to assess constructs from the TPB, developed in line with Ajzen's (1988) recommendations.

Attitude towards end-of-life decision making was measured by 2 items: participants were asked to indicate whether they were comfortable talking about death and dying (item 14) and whether they were comfortable talking about end-of-life care, such as resuscitation and advance care planning (item 15). Responses were measured on a 4-point scale ranging from 1 = 'strongly agree' to 4 = 'strongly disagree'. These items were highly correlated ($r = .82$, $p < 0.01$). The mean rating of these items were used for further analysis. The internal consistency of the scale was satisfactory (alpha = 0.90).

A high score on this item indicates less favourable attitudes towards end-of-life decision making.

Attitude towards discussing end-of-life issues with doctors was measured by a 6-item scale asking participants to rate the extent to which they think that talking about end-of-life issues with the doctor would be 'very good to very bad', 'very helpful to very unhelpful', 'very negative to very positive' 'very harmful to very beneficial', 'very satisfying to very unsatisfying' and 'very useful to very useless' (see items 18-23). The negatively worded scales were recoded. Principle component analysis followed by oblique rotation on the six items resulted in only one factor with an eigenvalue of greater that 1 accounting for 63.26 % of the variance. The factor was labeled 'Attitudes towards discussing end-of-life issues with doctors'. For analysis the mean rating of the 6 items were used. The internal consistency of the scale was satisfactory (alpha = 0.90). A high score in this scale indicates less positive attitude towards discussion end-of-life issues with doctors.

Subjective norms, perceived behavioural control and intentions. Unless otherwise stated the items were measured on a 4-point response scale ranging from 1 = 'strongly agree' to 4 = 'strongly disagree'. *Subjective Norms* were measured by a single item 'My family thinks that I should discuss end-of-life issues with my doctor' (item 57). *Perceived Behavioural Control* was measured by 2-items, 'If I wanted to discuss end of-life issues with my doctor I could do so' (item 58) and 'It would be difficult for me to discuss end-of-life issues with my doctor' (item 59). This item was re-coded. The two items were moderately correlated with each other ($r = .27$); since the correlation was low, only a single item measure of perceived behavioural control was used (item 59). *Intentions to discuss end-of-life issues with doctor* were measured using five items 'I plan to discuss end-of-life issues with my doctor'(item 60), 'I intend to talk about end-of-life issues with my doctor in the next 6 months' (item 56), 'I want to talk to my doctor about the options for end-of-life care' (item 28), 'I feel the need to talk to my doctor about end-of-life issues' (item 34) and 'I feel that discussing end-of-life issues with my doctor' is irrelevant at this point in my life' (item 33). This item was recoded. Principle- component analysis followed by oblique rotation on the five items resulted in only one factor with an eigenvalue greater than 1. The factor accounted for 55.38 % of the variance suggesting that these items formed one factor labeled 'Intentions to discuss end-of-life issues with their doctors'. For analysis the mean of the five items was used. The internal consistency of the scale was satisfactory (alpha = 0.82). Higher score indicate lower scores in subjective norms, perceived behavioural control and intentions.

Discussion of end-of-life issues with doctor and family members

Participants were also asked if they had initiated end-of-life conversation with their doctors and family members ('Yes' or 'No') and asked to indicate how satisfied they were with these conversations on a 4-point Likert scale, where 1 = 'strongly agree' and 4 = 'strongly disagree'.

Living Wills

Participants were asked if they had heard what a living will is (item 65) and could answer 'Yes' or 'No'. Participants who answered 'Yes' were asked to briefly describe a living will (item 66). This was an open ended question; participants who had no knowledge were given a score of 0, an accurate knowledge a score of 1, and limited or inaccurate knowledge a score of 2. Further, participants were asked to indicate if they had a living will by answering 'Yes' or 'No' (item 67). Participants who had living wills were asked if their doctor knew about the signed living will (item 68), where it was stored (item 70) and who helped them write the living will (item 69). These items were open-ended questions.

Participants were asked the following questions to assess constructs from the TPB, developed in line with Ajzen's (1988) recommendations. These items were measured on a 4-point response scale ranging from 1 = 'strongly agree' to 4

= 'strongly disagree'. *Subjective Norms to write a living will* were measured by a two items 'My family thinks that I should sign a living will' (item 73) and "My doctor thinks that I should sign a living will' (item 74). These items were highly correlated, r = .72. The internal consistency of the scale was satisfactory (alpha = .83). For analysis the mean of the items was used. *Perceived Behavioural Control to write a living will* was measured by 2 items: 'If I wanted to write a living will tomorrow, I could do' (item 75) and 'It would be difficult for me to sign a living will' (item 76). Item 76 was recoded. These items were not correlated with each other and hence only recoded item 76 was used for further analysis. *Intentions to sign a living will were* measured using a single item 'I intend to sign a living will in the next 6 months' (item 72). A higher score on these items indicates less favorable subjective norms, less perceived behavioural control and lower intentions towards signing a living will.

Death Anxiety Scale (DAS)

The DAS (Templer, 1970) measures an individual's attitudes towards death-related topics. The DAS is a 15-item, true/false scale that yields a composite score (See items 82 - 86). The measure has a reported test-retest reliability correlation coefficient of .83, the internal consistency assessed by Kuder-Richardson KR-20 was .76, and has been used in a variety of studies including ones on end-of-life issues (Palker & Nettles-Carson, 1995).

Hierarchical agglomerative clustering of the 15-item Death Anxiety Scale (DAS) (employing between-group linkages and squared Euclidean distance) was run. Four of the 15 items were reversed (item 83, 86, 87, 88), as they were negatively phrased. In clustering techniques it is often difficult to decide on the appropriate number of clusters. In this instance the dendogram was examined closely by examining the differences between fusion levels in the dendrogram produced by the statistical package (as recommended by Everitt, 1993). The figure revealed that two clusters (See Appendix 11). On closer inspection it was found that all 4 items in the smaller cluster (items 83, 86, 87 and 88) were phrased as double negatives and hence were cognitively 'complex' items. There appeared to be more missing values on these 4 items and hence the smaller of the two clusters, the four negatively phrased items were removed and excluded from further analysis, leaving 11 positively coded items. By removing these negatively phrased items it is possible that the scale measured a yea-saying response bias. Next, the reliability coefficients of the 11- item scale were examined. The alpha improved from 0.60 to 0.65 by removing item 96. Hence, only 10 items were included in the final Death Anxiety scale score. The mean of the 10 item were used for further analysis. Internal consistency assessed by Kuder-Richardson KR-20 of 0.70 or greater is considered an indicator of good internal reliability (Kline, 1993). The internal reliability of the Death Anxiety Scale is moderate and hence the results using this scale should be interpreted with caution.

Death Transcendence Scale

The Death Transcendence Scale (Hood & Morris, 1983) originally contained 23-item with a 4-point response format. The items assess how individuals implicitly wish to be remembered after they die. It is based on the premise that perspectives concerning death transcendence relate to other consciously held perspectives on death. Only the 5-item religious subscale of the Death Transcendence Scale was included in the questionnaire (e.g. 'Death is a transition to something even greater in life'). (See items 97- 101). Principle-component analysis followed by oblique rotation on the five items resulted in only one factor with an eigenvalue of greater that 1. The factor accounted for 76.55 % of the variance hence was labeled 'Death Transcendence Score'. The internal consistency of the scale was satisfactory (alpha = .93). For analysis the mean of the scores was used.

Duke Religious Index

The Duke Religious Index (Koening, Patterson, & Meador, 1997) measures major dimensions of religiousness. Only the subscale of the Duke Religious Index measuring intrinsic religiosity was used in the questionnaire (items 102-107). In addition an item was added to the scale to assess the relevance of religious beliefs in making end-of-life decisions. Principle- component analysis followed by oblique rotation on the items resulted in only one factor with an eigenvalue of greater that 1. The factor accounted for 78.90 % of the variance and was labeled 'intrinsic religiosity' score. The internal consistency of the scale was satisfactory (alpha = .94). For analysis the mean of the scores was used.

6.4.2.2 Time 2 questionnaire

The follow-up questionnaire (Time 2, see Appendix 10), was sent six months after participants completed Time 1 questionnaire.

Discussing end-of-life issues with doctors

The behaviour component of the TPB was assessed by asking participants whether they had spoken to their doctors about end-of-life issues in the past 6 months (item 1) and if they had ever spoken to their doctors about end-of-life issues before (item 2). Participants answered 'Yes' or 'No' to these questions. If participants had answered 'Yes' to either of these questions they were asked to proceed to item 3, or if they answered 'No' to both the questions they were asked to proceed to item 14. Participants answering 'Yes' to item 1 and/or item 2, were further asked to indicate whether the discussion included living wills, CPR, DNAR, death and dying and nutrition/ hydration (item 3). All participants indicated that the discussion with their doctor indicated one or more of these end-of-life issues. Participants were asked to indicate if a 'family member, friend, religious guide, other medical professional or nobody' was present during the discussion (item 4). Participants were asked to indicate whether 'the presence of other medical professionals helped me talk about these issues (if relevant)' (item 5) and whether 'the presence of my family members helped me talk about these issues (if relevant)' (item 6). These were measured on a 4-point Likert scale from 1 = 'strongly agree' to 4 = 'strongly disagree'.

Participants were asked the following questions about their discussion with their doctor: PBC was measured by asking participants if they found talking to their doctors about these issues difficult (item 10). This item was recoded.

Subjective Norms was measured by a single item measure 'My family thinks that I should discuss end-of-life issues with my doctor' (item 11). These were both measured on a 4-point Likert scale from 1 = 'strongly agree' to 4 = 'strongly disagree', and were identical to their equivalent Time 1 measures. Satisfaction with the conversation was measured by a 2-item measure, 'I was satisfied with the conversation' (item 7) and 'I am content with the conversation I had with the doctor' (item 12). These were measured on a 4-point Likert scale from 1 = 'strongly agree' to 4 = 'strongly disagree'. These items were highly correlated with each other ($r = .93$) and hence the mean of the items were used for further analysis.

Furthermore, participants who had not discussed these issues with their doctors were assessed on their current intentions to discuss these issues with their doctors (item 14-17). Principle component analysis followed by oblique rotation on the four items resulted in only one factor with an eigenvalue greater that 1. The factor accounted for 95.89 % of the variance suggesting that these items formed one factor labelled 'Intentions to discuss end-of-life issues with the doctor in Time 2'. The internal consistency of the scale was satisfactory (alpha = .91). For analysis the mean of the four items was used. Subjective norms was measured by a single item measure 'My family thinks that I should discuss end-of-life issues with my doctor' (item 27). PBC was measured by asking participants 'I think it will be difficult for me to discuss end-of-life issues with my doctor'. This item was recoded (item 28). These were again measured on a 4-point Likert scale from strongly agree to strongly disagree, and were identical to Time 1.

Practical barriers to having end-of-life discussions with the doctor was measured with a 6-item scale: 'I wanted to have this discussion but practical barriers prevented them from doing so' (item 18). Participants were asked to specify whether they thought that they did not have the time to discuss these issues with their doctors (item 19), do not know enough about end-of-life issues to discuss it with the doctor (item 20), kept putting it off (procrastination) (item 22), do not like thinking about these issues (item 23), doctor has no time for these discussions (item 24). These were measured on a 4-point Likert scale from 1 =

'strongly agree' to 4 = 'strongly disagree'. These items were used separately in the analysis.

The subjective norms of those who had discussed end-of-life issues with their doctors and those who had not discussed these issues with their doctors were combined (item 11 and item 27). Similarly, the perceived behavioural control measure of those who had discusses and not discussed these issues with their doctors were combined (recoded item 10 and recoded item 28).

Signing a living will

The *behaviour component* of the TPB was assessed by asking whether they had signed a living will in the last six months (item 29) and whether this was the first time they had written a living will (item 30), by answering 'Yes' or 'No'. If participants had answered 'yes' to either of these questions they were regarded as performing the behaviour and asked to proceed. If participants answered 'No' to either of these questions, they were asked to go to item 40.

Participants who answered 'Yes' on the behaviour component were asked the following questions about their experience of signing a living will: perceived behavioural control was measured by asking participants if it was difficult to sign a living will (item 35). This item was recoded. Subjective norms were measured by 2-items: 'My family thinks that I should sign a living will' (item 36) and 'My doctor thinks I should sign a living will' (item 38). These item correlated with each other (r = .56) and hence the mean of these scores was used for further analysis. The internal consistency of the score was acceptable (alpha = .72). Satisfaction with the conversation was measured with a 2-items, 'I was satisfied that I have signed a living will' (item 32) and 'I am content that I have signed a living will' (item 37). These 2 items were correlated with each other. These were measured on a 4-point Likert scale from 1 = 'strongly agree' to 4 = 'strongly disagree', and were identical to Time 1 measures.

Furthermore, participants who had not signed a living will were assessed on their intentions to discuss these issues with their doctors (item 41). Subjective norms were measured by a 2-item measure 'My family thinks that I should sign a living will' (item 53) and 'My doctor thinks I should sign a living will' (item 55). The two items were highly correlated with each other (r = .97). The internal consistency of the score was consistent (alpha = .69). Perceived behavioural control was measured by asking participants 'I think it will be difficult for me to sign a living will' (item 54). This item was recoded. These were measured on a 4-point Likert scale from 1 = 'strongly agree' to 4 = 'strongly disagree', and were identical to Time 1. Participants were also asked to indicate whether they wanted to sign a living will, but practical barriers prevented them from doing so (item 44). This was assessed on a 4-point Likert scale ranging from 1 = 'strongly agree' to 4 = 'strongly disagree'. Participants were asked to specify whether they thought that they did not have the time (item 45), do not know enough about living wills (item 46), kept putting it off (procrastination) (item 49), do not like thinking about these issues (item 48), tried talking about signing a living will but their doctor and family did not want to (item 51) and 'My doctor and family do not have time to discuss the living will.

The subjective norms of those who had signed living wills and those who had not signed living wills were combined (mean of items 53 and 55 and the mean of 36 and 38). Similarly, the perceived behavioural control measure of those who had signed and not signed living wills were combined (item 54 and item 35).

6.4.3 Procedure

At Time 1, participants who had volunteered to participate, and who had either spoken to the author on the phone or in person, were sent a copy of the information sheet (see Appendix 6), consent form, the questionnaire and a freepost envelope to return the completed questionnaire. Participants were also provided with a list of organisations that could provide information on living wills and resuscitation (see Appendix 3). Participants were given the option of a follow-up call from the researcher after completing the questionnaire.

Approximately six months later at Time 2, participants who had agreed to participate in future studies were sent a letter explaining this phase of the study (see Appendix 8), copy of the information sheet (see Appendix 9), the follow up questionnaire (see Appendix 10) and a freepost envelope to return the completed questionnaire. The option of a follow-up call was provided. As the initial wave of Time 2 data collection had a low response rate, participants were called and reminded to fill in the questionnaire and where necessary another copy of the questionnaire was resent.

6.5 Statistical analysis

Statistical analysis was carried out using SPSS 11.0. The results were analysed in the following ways.

- The approach used for the psychometric evaluation of measures included constructing them empirically by a) Pearson's correlations (if it was a 2-item measure), b) use of factor extraction (in the case of 3 or more item measures). Principle component analyses and oblique rotation were conducted on multi-dimensional scales to determine whether the components were consistent with the existing theoretical constructs. Factors with an eigenvalue of 1 or more were retained; c) Cluster analysis (Hierarchical agglomerative clustering, employing between-group linkages and squared Euclidean distance) was used if the items were dichotomous, as in the construction of the Death Anxiety Scale, and d) conceptually by forming scales based on the authors' original theoretical constructs. Missing data were replaced with means. The Cronbach alpha reliability coefficients of empirically derived and conceptually derived constructs were obtained. Items were deleted if their deletion increased the Cronbach alpha value of the new scale. The Cronbach alpha was calculated for participants who had participated in both Time 1 and Time 2.
- At Time 1, demographic characteristics of all participants were obtained. The demographic statistics of participants who took part in the follow up study were compared with the sample that dropped out, by using Chi Squares.

- In addition, independent samples t-tests were used to compare the sample who participated at Time 2, with those who had dropped out in all measures.
- Descriptive, exploratory analysis was conducted to determine the knowledge of CPR and knowledge about living wills. Independent sample t-tests were conducted to determine whether perceived success rates influences choice of CPR.
- Further, paired sample t-tests using Bonferroni correction was used to determine whether older people wish to discuss end-of-life issues with their doctors and family members and why they had this preference.
- Pearson's product moment correlations were used to ascertain the directions and strengths of the relationship between two variables. Multiple regressions were performed to identify variables that predicted intentions to discuss end-of-life issues with their doctors. Similarly correlation and multiple regressions were conducted to identify variables that predicted intentions to sign living wills. The TPB constructs of attitudes, subjective norms and perceived behavioural control and variables that were correlated with intentions were used to predict intentions.
- Logistic regressions were used to examine the predictors of having or not having discussed end-of-life, having or not having signed a living will, at Time 2. Intentions, perceived behavioural control and dying with dignity measured at Time 1 were used to predict discussing end-of-life issues with doctors and to predict signing a living will.
- In addition, the role of past behaviour on predicting future behaviour was examined by using logistic regressions. Intentions, perceived behavioural control, dying with dignity and behaviour (discussed end-of-life issues at Time 1 or signing living will at Time 1) were used to predict discussing end-of-life issues with doctors and to predict signing a living will.
- Cross tabulations were used to examine the intention-behaviour gap. Descriptive statistics were used to explore why despite intending to

discuss end-of-life issues or to sign a living will, participants did not discuss end-of-life issues or sign a living will at Time 2. Practical barriers for individuals who intended to but did not perform the behaviour were examined.

6.6 Results

6.6.1 Participant Characteristics

Of the 149 questionnaires sent out at Time 1, 130 (87.25 %) returned the questionnaire. One participant died before returning the questionnaire, and 18 did not return the questionnaire or returned the questionnaire without filling it in. Of those 130 returned questionnaires, 10 were excluded because of the large number of missing data. One hundred and twenty participants were included in the final analysis, 43 men (35.8 %) and 77 woman (64.2 %). Forty-five of the participants (37.5 %) were between the ages of 60-69, 55 participants between the ages of 70-79 (45.8%), 17 (14.2 %) and 3 participants (2.5%) in the age groups 80-89 and over 90 respectively. The demographic characteristics of the participants are shown in Table. 6.1. The most endorsed religious affiliation (n = 57, 47.5 %) was Christianity. A large majority of the participants were white (n = 118, 98.3 %). The sample was well educated, 46 participants (38.3 %) had completed college and 46 (38.3 %) had graduate degrees. Half the sample lived alone (n = 61, 50.8 %), while another large proportion lived with family members (n = 52, 43.3 %). A substantial proportion of the participants were either widowed (n = 35, 29.2 %) or divorced or separated (n = 21, 17.5%). The income bracket of £10,000-20,000 was most frequently chosen by participants (n = 47, 39.2 %). The majority of the participants were currently retired (n = 106, 88.3 %). Most of the participants (n = 74, 61.7 %) had no long term illness and had not been hospitalised in the past 5 years (n = 64, 53.3 %).

Table 6.1: Demographic features of the participants at Time 1 (n = 120)

		No.	Percent
Gender	Male	43	35.8
	Female	77	64.2
Age	60-69	45	37.5
	70-79	55	45.8
	80 +	20	16.7
Religion	Christianity	57	47.5
	Hinduism	2	1.7
	Islam	2	1.7
	Judaism	2	1.7
	Buddhism	6	5.0
	Others	37	30.8
	Humanist Agnostic	4	3.3
	No religion	10	8.3
Ethnicity	White	118	98.3
	South-Asian	1	0.8
	Other ethnic background	1	0.8
Education	Secondary school	28	23.3
	College/ Post secondary	46	38.3
	Graduate degree	46	38.3
Living arrangement	Alone	61	50.8
	With family	52	43.3
	With friends	3	2.5
	Residential settling	4	3.3
Marital status	Single	13	10.8
	Married	51	42.5
	Widowed	35	29.2
	Divorced or separated	21	17.5
Annual Income	less than £10,000	45	37.5
	£ 10,000 – 20,000	47	39.2
	over £ 20,000	28	23.3
Occupational Status	Employer	1	.8
	Employee	6	5.0
	Retired	106	88.3
	Self-employed	4	3.3
	Others	3	2.5
Long-term illness	Yes	46	38.3
	No	74	61.7
Hospitalised in the past 5 yrs	Yes	56	46.7
	No	64	53.3
Source of recruitment	University of Third Age	13	10.8
	Old Feminist Network	11	9.2
	Voluntary Euthanasia Society	57	47.5
	OLDIE Magazine	2	1.7
	University of Surrey	8	6.7
	Day Care Centres	13	10.8
	Centre into research into ageing & gender	7	5.8
	Surrey Advertiser	1	.8
	Lunch Clubs	7	5.8
	Greater London Pensioners Society	1	.8

6.6.2 Comparing participant characteristics at Time 1 and Time 2.

Of the 120 questionnaires sent out at Time 2, 76 (63.33 %) were returned. Chi-squares revealed that there were significant differences between those who participated only in Time 1 and those who participated in Time 1 and Time 2 on age, education levels and annual income (see Table 6.2 below). Compared to those who dropped out, participants who complete both Time 1 and Time 2 questionnaires were younger, more educated and had higher incomes. Closer inspection of the numbers of participants revealed that participants from the Old Feminist Network, day care centers, centre into research into Ageing and Gender and lunch clubs were more likely to have dropped out from the study at Time 2.

Table 6.2: Demographic comparisons between participants who participated only in Time 1 and those who participated in Time 2.

		T1 (n = 44)		T1 & 2 (n = 76)				
		No.	%	No.	%	chi sq	df	p
Gender	Male	14	31.8	29	38.2	.49	1	.48
	Female	30	68.2	47	61.8			
Age	60-69	13	29.5	32	42.1	9.06	3	.03
	70-79	21	47.7	34	44.7			
	80 +	10	22.7	10	13.2			
Religion	Christianity	28	63.6	33	43.4	8.67	2	.06
	Others	3	6.8	19	25.0			
	None	13	29.5	24	31.6			
Education	Secondary school	17	38.6	11	14.5	9.67	3	.05
	Post secondary	15	34.1	31	40.8			
	Graduate degree	12	27.3	34	44.7			
Ethnicity	White	43	97.7	75	98.7	*		
	Others	1	2.3	1	1.3			
Liv. arrang	Alone	20	45.5	41	53.9	1.94	2	.59
	with others	24	54.5	35	46.1	76.0		
Marital status	Single	3	6.8	10	13.2	2.47	3	.65
	Married	18	40.9	33	43.4			
	Widowed	13	29.5	22	28.9			
	Separated	10	22.7	11	14.5			
Annual Income	less that £10,000	25	56.8	20	26.3	12.77	3	.03
	£ 10,000 - 20,000	12	27.3	35	46.1			
	Over 20,000	7	15.9	21	27.6			
Occ. Status	Retired	40	90.9	66	86.8	2.70	1	.61
	Others	4	9.1	10	13.2			
L.T. Illness	Yes	21	47.7	25	32.9	2.59	1	.11
	No	23	52.3	51	67.1			
Hospitalised	Yes	20	45.5	36	47.4	.04	1	.84
	No	24	54.5	40	52.6			
Source of recruitment	University of Third Age	-	-	13	17.1	*		
	Old Feminist Network	11	25	-	-			
	Voluntary Euthanasia Society	7	15.9	50	65.8			
	OLDIE Magazine	-	-	2	2.6			
	University of Surrey	-	-	8	10.5			
	Day Care Centres	10	22.7	3	3.9			
	Centre into research into ageing & gender	7	15.9	-	-			
	Surrey Advertiser	1	2.3	-	-			
	Lunch Clubs	7	15.9	-	-			
	Greater London Pensioners Society	1	2.3	-	-			

*Note - * denoted that chi-squares were not conducted as one cell or more had expected count cells less that 5*

6.6.3 Data Screening

All dichotomous variables were examined and none were eliminated from further analysis as there were none with uneven splits of more than 90/10 (Rummel, 1970). Univariate outliers were examined. To identify univariate outliers, the z scores for the computed scores were computed and all scores greater that +/- 3.29 were deleted from the analysis. Further, histograms were examined to exclude cases which looked like outliers. In this instance, no outliers were found. Missing values were treated by mean substitution.

The computed scores used for further analyses were examined for skewness and kurtosis. Histograms with constructed and the variable distribution was compared to the normal distribution (as suggested by Tabachnick & Fidell, 1996). No transformations were necessary.

6.6.4 Descriptive statistics of measures used in Time 1 and Time 2.

Table 6.3 provides the descriptive statistics for the constructs measured at Time 1.

Table 6.3: Descriptive statistics and alphas for constructs measured at Time 1 (n = 120)

Scale	No of items	Mean	SD	Alpha
Attitude towards end-of-life decision making	2	1.54	.51	.90
Attitude towards discussing end-of-life issues with doctors	6	1.85	.52	.90
Intentions to discuss EOL issues with doctor	5	2.32	.71	.82
Living Wills: Subjective Norms	2	2.70	.77	.83
Death Anxiety Scale (DAS)	10	1.68	.19	.65
Death Transcendence Scale (Religious subscale)	5	2.80	1.01	.93
Duke Religious Index	6	3.30	1.45	.94
Dying with Dignity Scale	5	1.38	.46	.61

Note: Low mean denotes more favourable attitudes towards end-of-life decision making, more favourable attitudes towards discussing end-of-life issues with doctors, more favourable intentions to discuss EOL issues with doctor and more favourable subjective norms. Lower means indicate more death anxiety, more death transcendence, and more religiosity, and higher values placed on dying with dignity.

Table 6.4 shows the descriptive statistics and alphas for the measures at Time 1 assessed on only the subset of n = 76 who completed both Time 1 and Time 2 assessments.

Table 6.4: Descriptive statistics and alphas for constructs measured at Time 1 for the subset of participants who completed both assessments (n = 76)

Scale	**No of Items**	**Mean**	**SD**	**Alpha**
Attitude towards end-of-life decision making	2	1.45	.53	.86
Attitude towards discussing end-of-life issues with doctors	6	1.78	.48	.89
Intentions to discuss EOL issues with doctor	5	2.46	.75	.84
Living Wills: Subjective Norms	2	.97	1.35	.87
Death Anxiety Scale (DAS)	10	1.69	.19	.69
Death Transcendence Scale (Religious subscale)	5	2.81	1.02	.93
Duke Religious Index	6	3.34	1.39	.93
Dying with Dignity Scale	5	1.37	.55	.63

Note: Low mean denotes more favourable attitudes towards end-of-life decision making, more favourable attitudes towards discussing end-of-life issues with doctors, more favourable intentions to discuss EOL issues with doctor and more favourable subjective norms. Lower means indicate more death anxiety, more death transcendence, and more religiosity, and higher values placed on dying with dignity.

To assess whether there were any significant differences in TPB measures and psychological constructs between those who dropped out at Time 2 (n = 44) and those who participated in both Time 1 and Time 2, independent sample t-tests were used. Table 6.5 reveals that in most comparisons there were no significant differences between groups. However there was a significant difference in attitudes towards end-of-life decision making. Those who dropped out at Time 2 tended to have less favourable attitudes towards end-of-life issues.

Table 6.5: Differences between participants in Time 1 only and participants who participated at Time 1 and Time 2 for TPB constructs and psychological constructs.

Scale	**Time 1 only (n = 44)**	**Time 1 and 2 (n = 76)**			
	mean (SD)	mean (SD)	t	df	p
Attitude towards end-of-life decision making	1.74 (.53)	1.43 (.55)	-2.93	118	.00
Attitude towards discussing end-of-life issues with doctors	1.83 (1.88)	1.88 (.50)	-.51	112	.61
Discuss with doc: Subjective norms	2.94 (.72)	2.58 (.85)	-2.00	112	.05
Discuss with doc: Perceived behavioural control	2.11 (.76)	1.95 (.75)	-1.09	111	.28
Discuss with doc: Intentions	2.61 (.72)	2.46 (.65)	-1.51	118	.14
Living Wills: Subjective norms	2.93 (.58)	2.59 (.84)	-1.49	118	.14
Living Wills: Perceived behavioural control	3.15 (.58)	3.26 (.94)	.48	112	.65
Living Wills: Intentions	2.87 (.92)	2.94 (.96)	.23	112	.81
Death Anxiety Scale (DAS)	1.67 (.20)	1.69 (.19)	.50	117	.62
Death Transcendence Scale (Religious subscale)	2.60 (1.08)	2.91 (.97)	1.58	109	.12
Duke Religious Index	3.09 (1.52)	3.43 (1.41)	1.23	118	.22
Dying with dignity Scale	1.47 (.46)	1.34 (.47)	-1.51	118	.13

Note: Low mean denotes more favourable attitudes towards end-of-life decision making, more favourable attitudes towards discussing end-of-life issues with doctors, more favourable intentions to discuss EOL issues with doctor and more favourable subjective norms. Lower means indicate more death anxiety, more death transcendence, and more religiosity, and higher values placed on dying with dignity.

6.6.5 Knowledge of Cardiopulmonary Resuscitation (CPR) at Time 1

Participants were asked about their knowledge of CPR and the DNAR and where they had heard about CPR. Ninety-seven participants (88.2 %) who had heard about CPR had also heard about the DNAR. A small proportion of participants (13, 11.8 %) had heard about CPR and not the DNAR. Six participants had heard of neither CPR nor DNAR, and only one participant had heard of the DNAR order and did not know what CPR was. A large proportion of the participants had heard about CPR from the television (43 participants, 35.8%)

and from the radio (31 participants, 25.8%). Other sources of information of CPR included lawyers (17 participants, 14.2%) and family members (5 participants, 4.2%), while only one had first heard about CPR from their doctor (0.8 %). Seven participants (5.7%) had other sources of information about CPR. Seventy-four participants had heard about CPR from the media, either the radio or television.

If they suffered a cardiac arrest, 21 participants (17.5 %) said they would like their lives prolonged by CPR whereas 57 participants (47.5%) would not like CPR attempted. Forty-one participants (34.2 %) were unsure or did not know their preferences for life-prolonging treatment (CPR). Participants were asked to indicate their perception of the success rates for CPR (see Table 6.6 below). A large proportion of the participants indicated that they did not know the success rate of CPR (46 participants, 38.3%) and a substantial number of participants (n = 29, 24.3 %) rated success rates between 20-50 %.

Table 6.6: Perceived success rates of CPR

Success rate of CPR	No. of participants	Percentage
Don't know	46	38.3
less than 20 %	22	18.3
20- 50 %	29	24.3
50-80 %	17	14.1
More than 80 %	6	5

An independent sample t-test was conducted to see if there was a relationship between participants' choice of wanting their lives prolonged by CPR (yes or no) in the event of cardiac arrests and their perceptions of success rates of CPR. The results indicate that participants who wanted their lives prolonged by resuscitation had higher perceptions of success rates (M = 2.47, SD = 1.86) than those who did not want their lives prolonged by resuscitation (M = 1.86, SD = .88), (t = 2.11, df = 48, p = 0.04).

There were no significant differences in perceived success rates between those participants who had acquired their knowledge of CPR through the media, either television or the radio (M = 2.07, SD = .87) and those who had acquired their knowledge through other sources (e.g. lawyer, doctors, books, in a hospital) (M = 2.19, SD = .06), (t = -.53, df = 68, p = .60).

6.6.6 Preference to Involve Medical Professionals or Family members in end-of-life decision making at Time 1

Participants were asked to indicate with whom they were most likely to discuss end-of-life issues. Forty-one participants (34.2 %) were most likely to discuss these issues with their spouses, 30 (25 %) with their children, 30 (25%) with their friends, 13 (10.8 %) with their doctors, 7 (5.8 %) with their siblings, 6 (5 %) with other medical professionals, 4 (3.3 %) with the clergy and 2 (1.7 %) with the nurse. Therefore, the majority of participants would rather discuss end-of-life issues with family members (spouses or children) than medical professionals (doctor, nurse or other medical professionals). More specifically, only 14 participants (11.7%) would rather speak to their doctors as compared to their family members (86 participants, 71.7%).

To explore older people's preferences for discussing end-of-life issues with family members and doctors, paired sample t-tests were conducted on various beliefs on the involvement of medical professionals (doctors) and family members' involvement in end-of-life decision making (see Table 6.7). A Bonferroni correction of 0.01 was set.

Table 6.7: Mean and Standard Deviations for beliefs about medical professionals and family members' involvement in end-of-life decision making at Time 1

Variable (items)	Medical Profs.			Family members					
	n	M	SD	n	M	SD	T	df	P
Trust (24 vs.37)	111	2.43	.81	111	1.73	.74	8.13	110	.00
Talk (28 vs. 41)	107	2.05	.89	107	1.75	.60	3.47	106	.00
Need (34 vs. 48)	103	2.46	.86	103	2.18	.81	2.99	102	.00
Irrelevance (33 vs. 47)	107	2.83	1.01	107	2.87	.96	-.37	106	.71
Uncomfortable (30 vs. 43)	105	2.97	.93	105	3.10	.78	-1.27	104	.21
Terminally ill (31 vs. 44)	107	2.75	1.03	107	2.98	.85	-2.38	106	.02

Note: A lower mean indicates more trust, more talk, more need, more irrelevance, more uncomfortable and more likely when terminally ill.

The results reveal that participants were more likely to trust family members than their doctors to make the right decision about their medical care, if they were to be very ill or in a coma. They were more likely to feel the need to and want to talk to their family members rather than medical professionals about the options in end-of-life care. In summary, the results suggest that older people had more positive beliefs about family members' involvement than medical professionals' involvement in end-of-life issues.

6.6.7 Knowledge about living wills at Time 1

A large proportion of the sample had good knowledge about living wills (n = 68, 56.7 %), while 24 participants (20 %) had poor knowledge and 26 (21.7 %) no knowledge of living wills. Further, 70 participants (58.3 %) had signed a living will, while 49 participants (40.8 %) had not signed a living will. Of the 70 participants who had signed a living will 60 (85.7 %) had informed their doctor about the living will. Twenty-four participants (34.4 %) had help writing the living will, while a large majority (58.6 %) had no help with writing the living will. In addition, participants who had living wills stored it either in their homes or with their GP's (43, 61.4 %). Chi-square was used to analyse whether there was a significant relationship between high knowledge about living wills and likeliness to have signed a living wills. Results revealed that participants who had high knowledge of living wills were likely to have signed a living will ($\chi2 = 48.632$; df = 2; $p<0.01$).

6.6.8 Correlates of intentions to discuss end-of-life issues with doctors at Time 1

Demographic variables (age and sex), constructs of the TPB (attitudes towards discussing end-of-life issues with doctor, attitude towards end-of-life issues, subjective norms and perceived behavioural control), dying with dignity scale, choice of CPR, Death Anxiety scale (DAS), Death Transcendence Scale (Death) and Duke Religious Index (Religiosity) were used to predict older people's intentions to discuss end-of-life issues with doctors. Pearson's product moment correlations were used when assessing the relationship between the variable. The inter-correlations between intentions, demographic factors and TPB constructs and other psychological measures are shown in Table 6.8.

Participants who had stronger intentions to discuss end-of-life issues with their doctors also tended to be women, and religious participants had less of an intention to discuss end-of-life issues with their doctors. Participants who had stronger intentions to discuss end-of-life issues with their doctors, had more positive attitudes towards discussing end-of-life issues with doctors and more positive attitudes towards end-of-life issues. These participants also tended to have higher subjective norms and higher perceived behavioural control. Consistent with the TPB, attitudes, subjective norms and perceived behavioural control were all positively correlated with intentions. In addition, participants who scored high on the dying with dignity scale also had higher intentions to discuss these issues with their doctors. Contradictory to expectations, choice of CPR was not associated with intentions or any other variables. Participants who had more favourable attitudes towards end-of-life issues, also had higher scores on the dying with dignity measure, had positive attitudes towards discussing end-of-life issues with doctors and had stronger perceived behavioural control over discussing end-of-life issues with their doctors. Participants who thought that they had control over discussing these issues with their doctors, had less anxiety towards death, positive attitudes towards end-of-life issues and felt that their families would have wanted them to discuss these issues with their doctors.

Table 6.8: Correlations between intentions to discuss end-of-life issues with doctors and demographic factors (age and sex) and values important when making end-of-life decisions and TPB constructs at Time 1 (n = 120)

	Mean (SD)	age	sex	das	religiosity	death	dwd	Att.eol	Att.doc	SN	PBC	Choice CPR
intentions	2.32 (.71)	.20	-.15*	.11	-.07	-.15	.27**	.29**	.28**	.58**	.37**	.15
age	2.82 (.77)		.07	.07	-.10	-.13	.09	.15	.08	-.08	.12	-.11
sex	1.64 (.48)			-.21*	-.00	.00	-.14	.08	-.01	-.03	-.07	.09
das	1.68 (.19)				-.06	.01	.14	-.15	-.06	.01	-.27**	-.14
religiosity	3.30 (1.45)					.80**	-.15	.01	.08	-.09	.019	-.14
death	2.80 (1.01)						-.16	-.03	-.07	-.09	-.03	-.02
dwd	1.38 (.46)							.31**	.17	.16	.17	-.06
Att.eol	1.54 (.56)								.20**	.20	.27**	.11
Att.doc	1.84 (.51)									.22	.26**	-.08
SN	2.71 (.81)										.29**	-.10
PBC	1.90 (.68)											-.11
Choice CPR	2.17 (.70)											

Note: intention – intentions to discuss end-of-life issues with doctor, das – death anxiety scale, religiosity - Duke Religious Index, death – Death Transcendence Scale, ATT-EOL- Attitudes towards discussing end-of-life, ATT-DOC- Attitudes towards discussing end-of-life with doctor SN- Subjective norms to discuss end-of-life issues with doctor, PBC- perceived behavioural control to discuss end-of-life issues with doctors. Lower mean indicates higher score.

6.6.9 Predicting intentions to discuss end-of-life issues with doctor at Time 1

A standard multiple regression analysis (independent variables that were significant at the univariate level were entered into the equation at once) was used to predict intentions to discuss end-of-life issues with doctors (see Table. 6.9). Variables that were significantly correlated with intentions at the univariate level were used as independent variables, namely gender, religion, attitudes towards discussing end-of-life issues with doctor, attitude towards end-of-life issues, subjective norms, perceived behavioural control and the dying with dignity scale. This approach of only including variables significant at the univariate level was considered appropriate as it restricts the number of predictors included in the analysis. A limitation of this approach is that it does not allow for the possibility of suppressor effects and therefore could overlook the effects of variables not included in the model. Tabachnick & Fidel (1996) suggested that correlations between predictive variables should be less than .70.to guard against multicollinearity. The correlates between the dependent variable were not above .70, ranging from -.15* to .58** and hence all the variables were included in the regression. The 7 variables were able to explain nearly 41 % of the variance in intentions to discuss end-of-life issues with doctor, adjusted $R^2 = 0.38$, (F (7,112) = 11.46, p<0.00).

Subjective norms, perceived behavioural control and gender were significant predictors of intentions to discuss end-of-life issues. More specifically, participants' beliefs about what their family thought about end-of-life issues (subjective norms), and their thoughts about whether they could discuss these issues with their doctors (perceived behavioural control) predicted whether they would intend to discuss end-of-life issues with their doctors. In addition, women were more likely to have higher intentions to discuss end-of-life issues with their doctors. Contrary to expectations, attitude towards discussing end-of-life issues with doctors, attitudes towards end-of-life decision making and dying with dignity were not significant predictors.

Table 6.9: Multiple regression predicting intentions to discuss end-life issues with doctors (Time 1)

	B	Std. Error	Beta	t	sig
Gender	-.22	.11	-.15	-2.02	.04
Religion	-2.10	.02	-.11	-1.46	.15
Attitude towards EOL decision making	.12	.10	.09	1.15	.25
Attitudes towards discussing EOL with doc	.13	.11	.09	1.17	.24
Subjective norms	.43	.08	.41	5.51	.00
Perceived behavioural control	.29	.03	.27	3.49	.00
Dying with dignity	.11	.12	.07	.90	.37

Note: Lower means denote higher scores

6.6.10 Correlations of intentions to sign a living will at Time 1

Demographic variables (sex and age), constructs of the Theory of Planned Behaviour (attitudes towards discussing end-of-life issues with doctor, attitude towards end-of-life issues, subjective norms and perceived behavioural control), dying with dignity scale, choice of CPR, Death Anxiety scale (DAS), Death Transcendence Scale (Death) and Duke Religious Index (Religiosity) were used as a theoretical framework to predict older people's intentions to sign a living will. Pearson's product moment correlations were used to assess the relationships between the constructs. The inter-correlations between intentions, demographic factors and TPB constructs and other psychological measures such as dying with dignity measure, Death Anxiety scale (DAS), Death Transcendence Scale (Death) and Duke Religious Index (Religiosity) are shown in Table 6.10.

The results suggest that older people intending to sign a living will have higher subjective norms and higher perceived behavioural control. Therefore participants who intended to sign a living will were more likely to think that their doctors and family members wanted them to do so and also felt that they had control over these issues. Contrary to expectations, choice of CPR and dying with dignity was not associated with intentions. Attitude towards end-of-life decision making is significantly associated with dying with dignity and knowledge of living wills. Participants who had stronger perceived behavioural control also had more favourable attitudes towards the end-of-life decision making and subjective norms.

Table 6.10: Correlations between intentions to sign living will, demographic variables and values important when making end-of-life decisions and TPB constructs.

	Mean (SD)	age	sex	das	rel	death	dwd	knowledge of lw	Att.eol	SN	PBC (58)	Choice CPR
int.lw	.97 (1.47)	.13	-.16	.16	-.02	.02	-.01	.10	.11	.82**	.49*	-.10
age	2.82 (.77)		.07	.07	-.10	-.13	.09	.19	.15	-.13	.24	.17
sex	1.64 (.48)			-.21*	-.00	.00	-.14	.02	.08	-.21	-.04	.09
das	1.68 (.19)				-.06	.01	.14	.06	-.15	.09	.06	.16
rel	3.30 (1.45)					.80**	-.15	-.20	.01	-.07	-.14	-.02
death	2.80 (1.01)						-.17	-.20	-.03	-.00	-.19	.02
dwd	1.38 (.46)							.22*	.31**	.20	.23	-.04
knowl of lw	1.01 (.60)								.36**	.01	.04	.03
Att.eol	1.54 (.56)									.12	.32*	.11
SN	.97 (1.36)										.45*	-.01
PBC	1.62 (1.77)											-.11

Note: int.lw – intentions to sign a living will, das – death anxiety scale, religiosity - Duke Religious Index, death – Death Transcendence Scale, ATT-EOL- Attitudes towards discussing end-of-life, SN- Subjective norms to sign a living will, PBC- perceived behavioural control to sign a living will. Lower mean indicates higher score..

6.6.11 Predicting intentions to sign a living will at Time 1

A standard multiple regression analysis (independent variables were entered at the same Time) was used to predict intentions to sign a living will (see Table. 6.11). A similar approach as used for predicting intentions to discuss end-of-life issues with doctors was used. Variables that were significantly correlated with intentions at the univariate level were used as independent variables to restrict the number of predictors, namely subjective norms and perceived behavioural control. Attitudes were also added in the regression, in accordance with the TPB. The correlations between the predictive variables were under .70, ranging from .32* to .45* and therefore all were included in the regression. The 3 variables were able to explain nearly 35 % of the variance in intentions to sign a living will, adjusted $R^2 = 0.33$, ($F(3,116) = 21.22$, $p<0.00$).

Subjective norms and perceived behavioural control were significant predictors of intentions to sign a living will. More specifically, participants' beliefs that their family thought about they should sign a living will (subjective norms) and their thoughts about whether they could discuss these issues with their doctors (perceived behavioural control) predicted their intentions to sign a living will.

Table 6.11: Multiple regression predicting intentions to sign a living will (Time 1)

	B	Std. Error	Beta	t	sig
attitude towards eol decision making	-3.25	.07	-.03	-.45	.65
Subjective norms	.53	.09	.45	5.65	.00
Perceived Behavioural Control	.32	.09	.28	3.50	.00

6.6.12 Discussing end-of-life issues with doctors at Time 2

At Time 1, 46 (38.3 %) had discussed end-of-life issues with their doctors and 72 participants (60 %) had not discussed these issues with their doctors. By the follow-up at Time 2, 41 participants had discussed end-of-life issues with their doctors in the past 6 months. However, only 18 participants had discussed these issues with their doctors for the first time in the past 6 month, while 23 had discussed these issues previously at Time 1 and also at Time 2. See Table 6.12 for details.

Table 6.12: Participants who had discussed end-of-life issues with doctors at Time 1 and/or Time 2

	Discussed at Time 2	discussed for the 1st Time at time 2	past behaviour (discussed at Time 1)
Yes	41 (53.9)	18 (41.9)	23 (69.7)
No	35 (46.1)	25 (58.1)	10 (30.3)

6.6.13 Predictors of group membership: discussed end-of-life issues with doctors at Time 2

According to the TPB, intentions to discuss end-of-life issues and perceived behavioural control should predict the behaviour or having a discussion about end-of-life issues with doctors. It had also been hypothesised that higher values on dying with dignity would predict discussion about end-of-life issues with doctors. To evaluate these predictions, all participants who reported at Time 2 that they had discussed end-of-life issues with their doctors in the preceding six months were categorised as having had the discussion, irrespective of whether they had also discussed these issues in the past (prior to Time 1 and at Time 1). The three predictors were: intentions, perceived behavioural control, and dying with dignity.

Hosmer-Lemeshow goodness of fit test was non-significant (Chi-square = 6.00, df = 8, p= .65 > 0.05), suggesting that the prediction fit the model. A test of the full model against a constant-only was statistically significant. Using this set of predictor variables, approximately 66.7 % of the cases were correctly classified, which was considered reasonably good. Table 6.13 shows the regression coefficient, standard error, Wald statistic, odds ratio and 95 % confidence interval for each predictor variable.

Table 6.13: Logistic regression predicting discussing end-of-life issues with doctor

	B	S.E.	Wald	df	Sig.	OR	95 % C.I.for EXP(B)
intentions	.65	.39	2.79	1	.09	1.92	.89- 4.25
PBC	.57	.45	1.65	1	.20	1.77	.74- 32.71
dying with dignity	2.07	.72	8.25	1	.00	7.95	1.93- 32.71

Model chi-square 20.13, df = 3, p =.000; PBC: Perceived behavioural Control to discuss end-of-life issues with doctor

According to the Wald criteria only dying with dignity was significant (see Table 6.15). The OR for dying with dignity indicates that with every one unit increase in the value for dying with dignity the participants was 7.95 times more likely to have discussed end-of-life issues with their doctor

To determine whether past behaviour affected discussing end-of-life issues with the doctors, the regression was repeated including whether or not the participant had discussed these issues with their doctor at Time 1 (past behaviour) as a predictor. Hosmer-Lemeshow goodness of fit test was non-significant (Chi-square = 4.78, df = 8, p= .78 > 0.05), suggesting that the prediction fit the model. A test of the full model against a constant-only was statistically significant. Using this set of predictor variables, approximately 69.4 % of the cases were correctly classified, which was considered reasonably good. Table 6.14 shows the regression coefficient, standard error, Wald statistic, odds ratio and 95 % confidence interval for each predictor variable.

Table 6.14: Logistic regression predicting discussing end-of-life issues with doctor (with past behaviour)

	B	S.E.	Wald	df	Sig.	OR	95 % C.I.for EXP(B)
intentions	.47	.43	1.21	1	.27	1.61	.68 – 3.76
PBC	.64	.47	1.87	1	.17	1.91	.76 – 4.80
dying with dignity	1.95	.72	7.40	1	.01	7.06	1.72 – 28.87
past behaviour	.59	.64	.860	1	.35	1.80	.52 – 6.26

Model chi-square 20.98, df = 4, p =.000, Perceived behavioural Control to discuss end-of-life issues with doctor

Past behaviour did not predict discussion with doctors at Time 2. According to the Wald criteria only dying with dignity was significant (see Table 6.14). The OR for dying with dignity indicates that for every one unit increase in the predictor dying with dignity the participants was 7.06 times more likely to have discussed end-of-life issues with their doctor.

As reported above, and contrary to expectations, attitudes towards end-of-life issues and attitudes towards discussing end-of-life issues with doctors, did not predict intentions to discuss end-of-life issues with the doctor. Therefore, as an exploratory post-hoc analysis, attitudes towards end-of-life issues, attitudes towards discussing end-of-life issues with doctors and dying with dignity were used to predict discussing end-of-life issues with the doctors. Hosmer-Lemeshow goodness of fit test was non-significant (Chi-square = 7.70, df = 8, p= .46 > 0.05), suggesting that the prediction fit the model. A test of the full model against a constant-only was statistically significant. Using this set of predictor variables, approximately 71.8 % of the cases were correctly classified, which was considered reasonably good. Table 6.15 shows the regression coefficient, standard error, Wald statistic, odds ratio and 95 % confidence interval for each predictor variable.

Table 6.15: Logistic regression predicting discussing end-of-life issues with doctor (exploratory post-hoc analysis)

	B	S.E.	Wald	df	Sig.	OR	95 % C.I.for EXP(B)
dying with dignity	2.04	.74	7.56	1	.01	7.73	1.80 – 33.18
Att. EOL	.522	.57	.83	1	.36	1.69	.55 – 5.18
Att. DOC	1.66	.75	4.93	1	.03	5.27	1.21 – 22.85

Model chi-square 25.17, df = 3, p =.000 Define Att.EOL – Attitude towards end-of-life issues and Att.DOC - Attitude towards discussing end-of-life issues with doctor

According to the Wald criteria attitude towards discussing end-of-life issues with the doctor and dying with dignity was significant (see Table 6.15). The OR for towards discussing end-of-life issues with the doctor indicates that for every one unit increase of a positive attitudes towards discussing end-of-life issues with their doctors, the participants was 5.27 times more likely to have discussed end-of-life issues with their doctor. The OR for dying with dignity indicates that with every one unit increase in the predictor - dying with dignity the participants was 7.73 times more likely to have discussed end-of-life issues with their doctor.

6.6.14 Link between intentions to discuss end-of-life issues with doctors and discussing end-of-life issues with doctors at Time 2.

Contrary to expectations, intention to discuss end-of-life issues at Time 1, did not predict discussion with doctors at Time 2. Not all participants who intended to discuss end-of-life issues with their doctor reported having done so at Time 2. To examine the association between intentions and this behaviour, intention was converted into a categorical measure, participants who rated their intentions to discuss end-of-life issues with their doctors as 'strongly agree' or 'agree' were given a score of 'Yes', while participants who 'disagreed' or strongly disagreed were given a score of 'No'. Following from the works of Orbell & Sheeran (1998) and subsequently Rutter (2000), participants were categorized into 4 groups: intenders who discussed end-of-life issues with their doctors will be called 'inclined communicators'; intenders who did not discuss these issues with their doctors as 'inclined non-communicators'; non-intenders who discussed end-of-life issues with their doctors as 'disinclined communicators'; and non-intenders who did not discuss these issues with their doctors were called 'disinclined non-communicators'. The four groups are shown in Table 6.16

Table 6.16: Intention to discuss end-of-life issues with the doctor at Time 1 by reported having had such a discussion at Time 2

	Discuss	Not Discuss
Intend	Inclined Communicators (n = 29, 70.7 %)	Inclined non-communicators (n = 12, 29.3 %)
Not intend	Disinclined Communicators (n = 13, 37.1 %)	Disinclined non-communicators (n = 22, 62.9 %)

The group of most interest was the inclined non-communicators (n = 12). It was expected that practical barriers, would prevent participants who intended to perform these behaviours from performing the behaviour. The mean and SD's of the practical barriers are shown in Table 6.17. The most important reason for not discussing end-of-life issues for those who had intended to do so was the belief that their doctor did not have time for these discussions.

Table 6.17: Means and SD's of practical barriers for inclined non-communicators (n = 12)

Practical barriers	Mean	SD
My doctor does not have time for these discussions (item 24)	2.91	.94
Kept putting it off (procrastination) (item 22)	3.00	.89
I did not have the time (item 19)	3.09	1.04
Do not know enough about end-of-life issues (item 20)	3.09	1.14
Do not like thinking about these issues (item 23)	3.09	.94
I tried to talk about it but my doctor did not want to (item 25)	3.30	.95
Practical barriers prevented discussion (item 18)	3.45	1.04

Barriers rated on a 4 point scale: 1 = strongly agree, 4 = strongly disagree

6.6.15 Signed a living will

At Time 1, 70 participants (58.3 %) had signed a living will and 49 participants (40.8 % %) had not signed a living will. In the follow up at Time 2, 24 participants had signed a living will in the past 6 months. However, only 7 participants had signed it for the first time in the past 6 month, while 17 said they had signed a living will at Time 1 and also in the six months preceding Time 2. See Table 6.18, for details.

Table 6.18: Signed living will at Time 1 and/or at Time 2

	signed in Time 2	signed for the 1st time in Time 2	signed in Time 1 (past behaviour)
Yes	24 (31.6)	7 (29.2)	17 (34.7)
No	52 (68.4)	20 (74.1)	32 (65.3)

6.6.16 Predictors of group membership: signed a living will

All participants, irrespective of whether they had repeated the behaviour at Time 2, were used in the following analysis. According to the TPB, intentions to sign a living will at Time 1 and perceived behavioural control at Time 1, should predict signing living wills. In addition, it was hypothesised that higher values for dying with dignity would predict signing living wills. Therefore these three variables were used to predict whether or not participants reported having signed a living will in the past six months at Time 2.

Hosmer-Lemeshow goodness of fit test was non-significant (Chi-square = 7.86, df = 8, p= .45 > 0.05), suggesting that the prediction fit the model. A test of the full model against a constant-only was statistically significant. Using this set of predictor variables, we correctly classified approximately 72.1 % of the cases, which was considered reasonably good. Table 6.19 shows the regression coefficient, standard error, Wald statistic, odds ratio and 95 % confidence interval for each predictor variable.

Table 6.19: Logistic regression predicting signing a living will (without past behaviour)

	B	S.E.	Wald	df	Sig.	OR	95 % C.I.for EXP(B)
intention	-.00	.28	.00	1	.99	.99	.57 – 1.74
PBC	.06	.23	.06	1	.80	1.06	.67 – 1.67
Dying with dignity	1.45	.77	3.53	1	.06	4.27	.94 – 19.43

Model chi-square 5.02, df = 3, p = .000; Perceived behavioural Control to sign a living will

According to the Wald criteria dying with dignity was marginally significant (see Table 6.19). The OR for dying with dignity indicates that those who held dying with dignity as important when making this decision, were 4.27 times more likely to have signed a living will.

To determine whether past behaviour affected whether or not a person had signed a living will at Time 2, past behaviour was entered into the logistic regression in addition to intentions, perceived behavior control and dying with dignity. Hosmer-Lemeshow goodness of fit test was non-significant (chi-square = 8.75, df = 8, p= .36 > 0.05), suggesting that the prediction fit the model. A test of the full model against a constant-only was statistically significant. Using this set of predictor variables, approximately 72.1 % of the cases were correctly classified, which was considered reasonably good. Table 6.20 shows the regression coefficients, standard error, Wald statistic, odds ratio and 95 % confidence interval for each predictor variable.

Table 6.20: Logistic regression predicting signing a living will (with past behaviour)

	B	S.E.	Wald	df	Sig.	OR	95 % C.I.for EXP(B)
intentions	-.07	.35	.05	1	.83	.93	.47 – 1.83
PBC	.06	.23	.06	1	.81	1.06	.67 - 1.67
dying with dignity	1.33	.83	2.59	1	.11	3.80	.75 - 19.29
past behaviour	.36	1.01	.13	1	.72	1.44	.20 - 10.41

Model chi-square 5.15, df = 4, p =.272 Perceived behavioural Control to discuss end-of-life issues with doctor

As shown in Table 6.20, none of the variables was a significant predictor of signing a living will, despite the reasonably good classification of participants achieved by this model. This pattern of results may be due to effects introduced by using past behaviour as a predictor, given that past behaviour is itself a function of intentions, perceived behavioural control and dying with dignity.

As reported previously, attitudes towards end-of-life issues did not predict intentions to sign a living will at Time 1. A post-hoc exploratory logistic regression was conducted with attitudes towards end-of-life issues and dying with dignity as predictor variables and signing a living will as the dependent variable. Hosmer-Lemeshow goodness of fit test was non-significant (chi-square = 3.70, df = 6, p= .72 > 0.05), suggesting that the prediction fit the model. A test of the full model against a constant-only was statistically significant. Using this set of predictor variables, approximately 71.1 % of the cases were correctly classified, which was considered reasonably good. Table 6.21 shows the regression coefficients, standard error, Wald statistic, odds ratio and 95 % confidence interval for each predictor variable.

Table 6.21: Logistic regression predicting membership in signing living will (post-hoc analysis)

	B	S.E.	Wald	df	Sig.	OR	95 % C.I.for EXP(B)
Att.EOL	1.30	.59	4.84	1	.03	3.66	1.15 - 11.64
dying with dignity	.66	.64	1.06	1	.30	1.93	.55 - 6.79

Model chi-square 9.13, df = 2, p =.01

According to the Wald criteria only attitudes towards end-of-life issues was statistically significant (see Table 6.21). The OR indicates that those who had positive attitudes towards end-of-life issues, were 1.93 times more likely to have signed a living will. When attitudes were entered to the logistic regression, dying with dignity was not a significant predictor. This result may be due to the correlation between attitudes and dying with dignity (r = 0.33, p = 0.00). The variance previously accounted for by dying with dignity is now being accounted for by attitudes towards end-of-life issues.

6.6.16 Link between intentions to sign a living will and signing a living will

Similar to discussing end-of-life issues with doctors, intention to sign a living will at Time 1 did not predict signing of living wills at Time 2. Therefore, intention was converted into a categorical measure, participants who rated their intentions to sign a living will as 'strongly agree' or 'agree' were given a score of

'Yes', while participants who 'disagreed' or 'strongly disagreed' were given a score of 'No'. Participants were categorized into 4 groups: intenders who signed a living will, will be called 'inclined signers'; intenders who did not sign a living will as 'intended non-signers'; non-intenders who sign a living will as 'disinclined signers'; and non-intenders who did not sign a living will were called 'disinclined non-signers'. The four groups are shown in Table 6.22.

Table 6.22: Intention to sign a living will at Time 1 by signing a living will at Time 2

	Signed a living will	Not signed a living will
Intend	Inclined Signers (n = 10, 41.7 %)	Inclined Non-signers (n = 31, 59.6 %)
Not intend	Disinclined Signers (n = 14, 58.3 %)	Disinclined Non-signers (n = 21, 40.4 %)

The group of most interest was the inclined non-signers. It was expected that practical barriers, would prevent participants who intended to perform these behaviours from performing the behaviour. The mean and SD's of the practical barriers are shown in Table 6.23. The main reasons why participants, despite intending to did not perform the behaviour, was attributed to procrastination. Other reasons with relatively high agreement ratings were not knowing enough about living wills, doctors and/ or families did not have time for these discussions and they tried talking to their doctors and families about these issues but they did not want to.

Table 6.23: Mean and SD's of practical barriers for inclined non-signers (n = 21)

Practical barriers	Mean	SD
Kept putting it off (procrastination) (item 49)	2.69	2.81
Do not know enough about living wills (item 46)	2.81	1.05
My doctor and/or family do not have time for these discussions (item 50)	2.81	.83
I tried to talk about it but my doctor / family did not want to (item 51)	2.81	.91
Do not like thinking about these issues (item 48)	3.13	.83
Practical barriers prevented signing (item 44)	3.25	.58
Not have the time (item 45)	3.29	.47

Barriers rated on a 4 point scale: 1 = strongly agree, 4 = strongly disagree

6.7 Discussion

The present study, which employed a longitudinal design, examined descriptive data about older people's knowledge about advance care planning at Time 1. In addition, the study aimed to explore the role of the TPB and additional psychological constructs in predicting intentions to discuss end-of-life issues with doctors and/or to sign a living will and finally to predict whether older people discuss end-of-life issues with their doctors or sign living wills. TPB constructs and other psychological measures used at Time 1 were used to predict behaviour at Time 2.

Knowledge about CPR and living wills and preference to involve medical professionals or family members in end-of-life care

This study addressed three main exploratory descriptive questions: knowledge about CPR and its perceived success rates, preference to involve medical professionals or family members in end-of-life care and knowledge rates of living wills. A high proportion of older people who participated in the study had knowledge of CPR and the DNAR. However they tended to overestimate the survival rates of CPR, suggesting that despite having knowledge about these life-prolonging measures, this knowledge was not always accurate. Previous survey studies of hospitalised older people in the UK have shown similar results (e.g. Mead & Turnbull, 1995). Mead & Turnbull (1995) found that 80 % of their sample of 100 patients had heard about CPR, but tended to overestimate survival rates. The present study suggests that overestimating survival rates influences treatment choice, with those overestimating success rates of CPR wanting resuscitation conducted. Contrary to previous research, which suggests that the media contributes to the overestimation of CPR (Bruce-Jones et al., 1996; Mead & Turnbull, 1995), the results indicate that the media did not contribute to the unrealistic, overestimation of CPR. These results suggest that older people need to be educated about the success rates of CPR. A recent initiative by the BMA and the Resuscitation Council in producing a model CPR information sheet that can be used by local NHS trusts to educate patients about CPR and give them a realistic picture of survival rates, could benefit the general public. This would have important implications, as previous research has suggested that after being informed of actual survival rates, fewer older people wished to undergo CPR (Murphy et al., 1994).

Previous research in the UK suggests that older people had low knowledge rates about living wills and utilisation of advance directives tend to be low (e.g. Schiff et al, 2000; Seymour et al., 2004). However, the present results suggest that knowledge rates of living wills were good and a large proportion had signed living wills. This is probably reflective of a large majority of the sample being recruited via the Voluntary Euthanasia Society, which have living wills easily available and encourage its members to sign living wills.

Previous research has suggested that there is a large degree of variability in older patients' views on who should be involved in decisions regarding CPR (see Frank et al., 2003 for a review). The results of the present study suggest that older people had more positive beliefs to discuss end-of-life issues with their family than medical professionals and identified that the reason for this is because they trust family members more than their doctors to make the right decision about their medical care, if they were to be very ill or in a coma. They were hence more likely to feel the need to and want to talk to their family members rather than medical professionals about the options in end-of-life care. Therefore this study identified some reasons why older people prefer to discuss these issues with their families; however these need to be explored further.

Determinant of intentions to discuss end-of-life issues with doctors and sign living wills

Gender, subjective norms and perceived behavioural control predicted intentions to discuss end-of-life issues with their doctors. Intention to sign a living will was predicted by normative beliefs and perceived behavioural control. Contrary to expectations, the proposed additions to the TPB did not add to its predictive value to predict intentions to conduct advance care planning. The dying with dignity construct did show a relationship with intentions to discuss end-of-life issues with doctors at the univariate level, although dying with dignity was not associated with an intention to sign a living will. A diagrammatic representation of the determinants of intentions to discuss end-of-life issues with the doctors in presented in Figure 6.2 and the determinants of intentions to sign living wills is presented in Figure 6.3.

Figure 6.2: Diagrammatic representation of the predictors of intentions to discuss end-of-life issues with doctor at Time 1

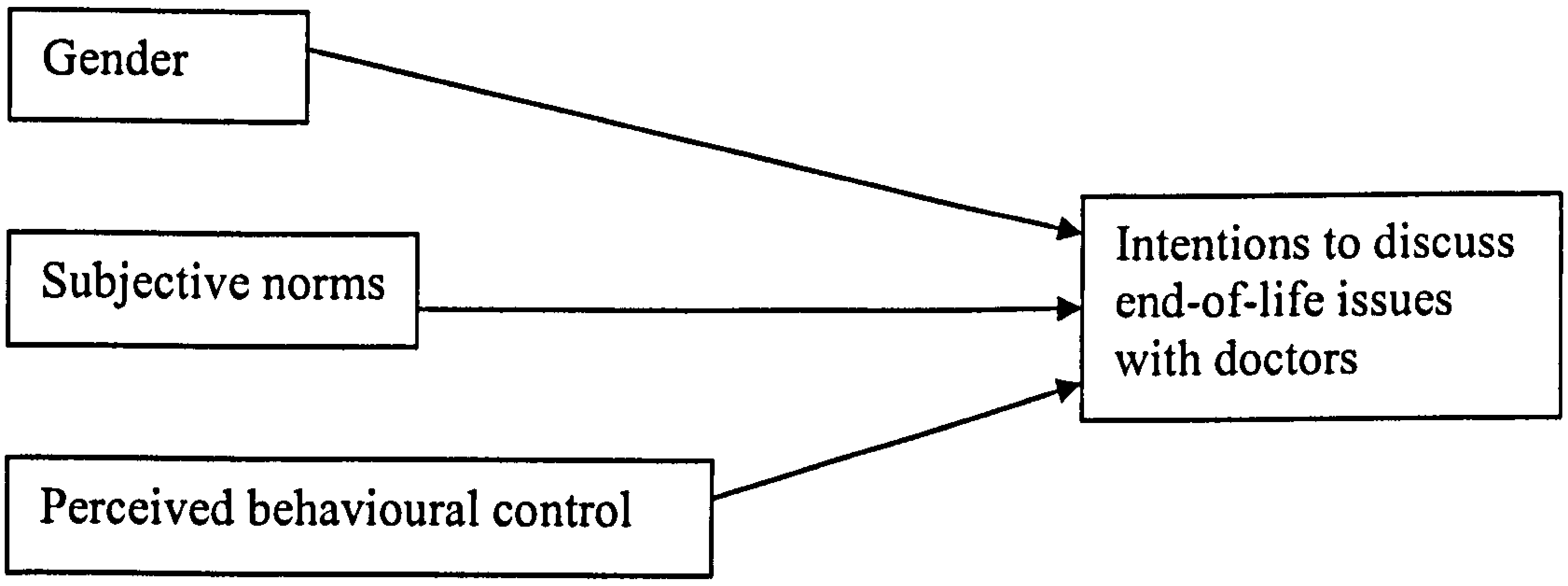
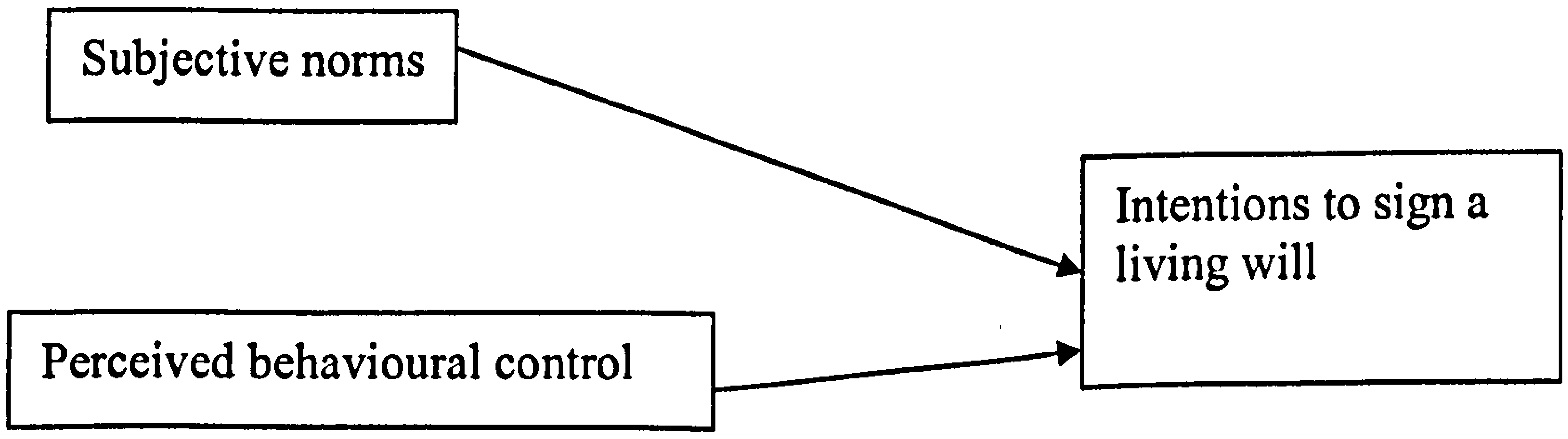


Figure 6.3: Diagrammatic representation of the predictors of intentions to sign a living will at Time



Women were more likely to intend to discuss these issues with their doctors. Previous research has suggested that women were less likely to want to undergo resuscitation (e.g. Lo, Saika & Strull, 1985; Schonwetter et al., 1994). Therefore it is possible that not wanting resuscitation could have made them want to discuss end-of-life issues with their doctors. However, contrary to expectations choice of resuscitation did not have an influence on intentions to discuss end-of-life issues with their doctors. The gender difference can also be attributed to woman being more likely to think about death and dying and wishing to make arrangements. In addition, women are more likely to discuss health issues with their doctors (e.g. Verbrugge, 1989).

Interestingly, subjective norms or the views that older people had about their families wanted them to discuss end-of-life issues with their doctors, as well as their normative beliefs about living wills, had a major impact on them intending to sign a living will. Not making end-of-life wishes known before incapacitation could leave family members the responsibility of making the decision on whether to prolong life. Therefore it seems reasonable that older people did take into account their own beliefs about what their families would have thought about these issues. In addition, advance care planning involves communication, either to gain information or to communicate their intentions for the use or non use of life prolongation, therefore older people's views about what their significant others thought about these issues would affect their decision to intend to conduct advance care planning. Other research using the TPB, examining novel and non-routine behaviours supports the importance of normative norms (e.g. Sutton, 1998).

The normative component was the last addition to the TRA (Fishbein & Ajzen, 1975), and several authors have argued that it is the weakest component. For example, Sheppard, Hartwick & Warshaw.'s (1988) meta-analysis found that the subjective norms component was the weakest predictor of intentions (also see Godin & Kok, 1996). As a result, several authors have deliberately removed subjective norms from the analysis (e.g. Sparks, Shepherd, Wieringa & Zimmermanns, 1995). The weaker predictive value of subjective norms in other studies could be attributed to the behaviours under consideration. The findings of this study support the predictive value of subjective norms in determining intentions to conduct advance care planning.

Ajzen (1991) has argued that moral norms may prove a useful addition to the TPB. Moral norms are regarded as the individual's perception of the moral correctness of incorrectness of performing a behaviour (Ajzen, 1991; Sparks, 1994) and take account of "personal feelings of ...responsibility to perform, or refuse to perform, a certain behaviour" (Ajzen, 1991, p.199). Moral norms could have an important influence on the performance of advance care planning, as they have a moral or ethical dimension. Randall & Gibson's (1991) study, which examined the use of the TPB in ethical decision making, included a measure of moral norms, which improved the prediction of intentions. However, moral norms were not measured in the study.

Perceived behavioural control or anticipated beliefs about whether this discussion and signing living will would be easy, predicted intentions to conduct advance care planning. Given the sensitive nature of these discussions, it seems reasonable to expect that older people who anticipated that discussing these issues with their doctors would be difficult would not intend to discuss these issues with their doctors. Previous research using the TPB has shown the importance of the PBC construct (see Armitage & Conner, 2001, for a review).

The conceptualisation of the PBC construct has received recent attention. Research using PBC has used 'self-efficacy' (e.g. ease/difficulty, confidence) and 'controllability' (e.g. personal control over behaviour, appraisal of whether the behaviour is completely up to the actor), and has shown low item internal consistency. Ajzen (1991, 2002) theorises no distinction between the causal effects of self-efficacy and controllability acts upon intentions, essentially inferring that the differences are meaningless and therefore can be used interchangeably. However, several authors (e.g. Terry, 1993) have suggested that self-efficacy and PBC are not entirely synomomous. For example, (Bandura, 1986, 1992) argues that control and self-efficacy are different concepts. Self-efficacy is more concerned with cognitive perceptions of control based on internal control factors, whereas PBC also reflects more general, external factors. Other researchers have proposed a distinction between 'perceived difficulty' and 'perceived control' (Sparks, Guthrie & Shepherd, 1997). A recent review of 11 empirical studies that have examined this item distinction suggests controllability and self-efficacy items can be reliably distinguished across a broad range of behaviours, with evidence of self-efficacy, as superior to controllability in predicting intentions (Trafimow, Sheeran, Conner & Finlay, 2002). In this study, PBC was measured by self-efficacy item or the ease or difficulty in predicting intentions to conduct advance care planning. It failed to take into account external factors that may affect individual's intentions to conduct advance care planning. PBC predictive intentions to discuss end-of-life issues with doctors and sign living wills but failed to predict behaviour. This non prediction of PBC in behaviour may be accounted for by the measurement of PBC only taking into account difficulty rather than including external factors.

Determinant of advance care planning: discussing end-of-life issues with doctors and signing living wills

Contrary to the TPB and expectations, intentions and perceived behavioural control measured at Time 1, did not predict discussion about end-of-life issues with doctors or signing a living will at Time 2. However, attitudes towards discussing end-of-life issues with doctors and dying with dignity predicted discussion with doctors at Time 2. With respect to signing living wills at Time 2, attitudes towards end-of-life issues predicted signing living wills at Time 2, while dying with dignity was marginally significant when past behaviour was not added to the regression. A diagrammatic representation of the determinants of discussing end-of-life issues with the doctors in presented in Figure 6.4 and the determinants of signing living wills is presented in Figure 6.5.

Figure 6.4: Diagrammatic representation of the predictors of discussing end-of-life issues with the doctors.

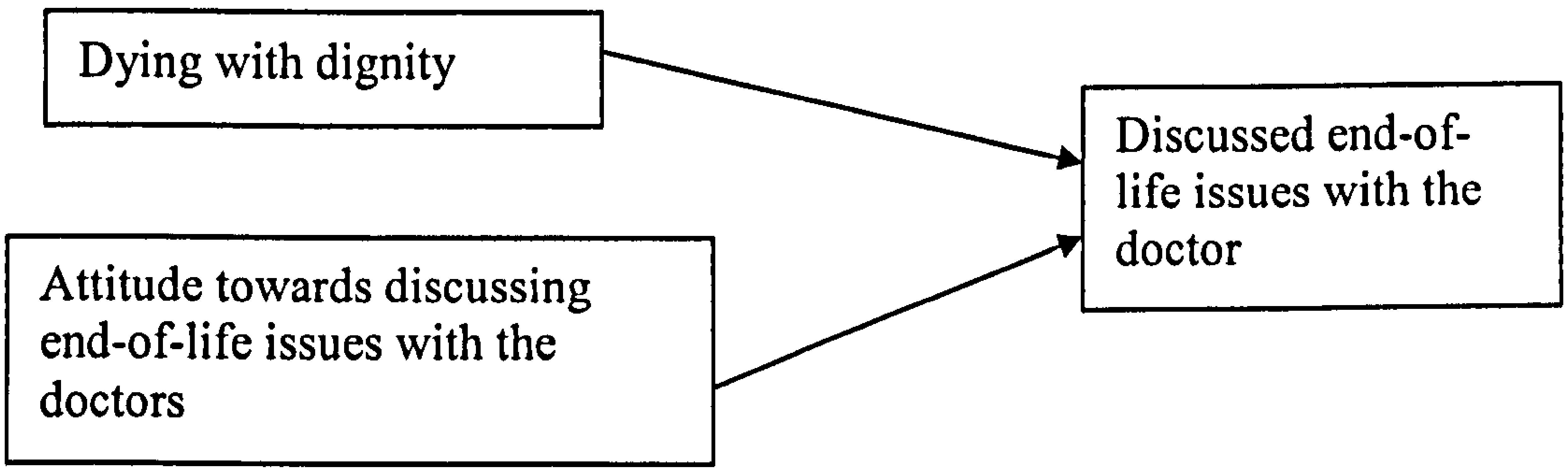
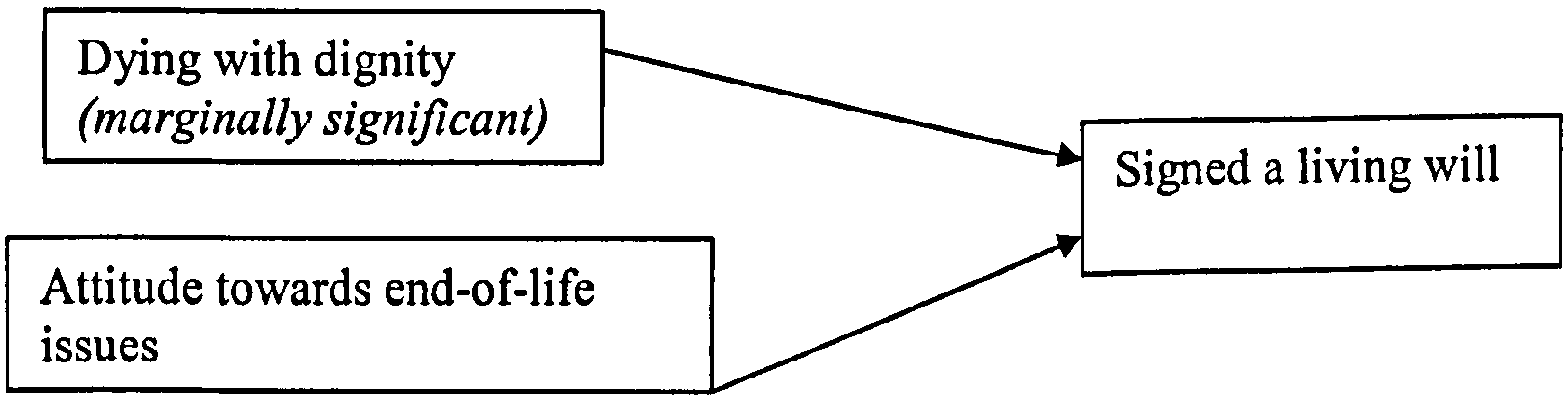


Figure 6.5: Diagrammatic representation of the predictors of signing living wills.



According to the TPB intentions of motivation to perform behaviour, mediate the relationship between attitudes and behaviour. Several studies have suggested that there can also be a direct influence of attitudes towards performing behaviour (e.g. Bagozzi, 1981; Ouellette & Wood, 1998; Triandis, 1977). In this case, attitudes towards discussing end-of-life issue and attitudes towards end-of-life care both were highly positive for the sample. In addition, those who dropped out at Time 2 tended to have less favourable attitudes towards end-of-life issues. It is possible that strong attitudes, because they are highly accessible in memory, became active automatically. Weaker attitudes are not activated automatically and therefore do not serve as spontaneous guides to behaviour. Fazio's (1990) Motivation and Opportunity as Determinants of Processing (MODE) theory provides support for this view.

Attitudes predicted advance care planning for both discussion with doctors and signing of living wills. More specifically, attitudes towards discussing end-of-life issues with the doctor predicted discussion with doctor, while attitudes towards end-of-life issues predicted signing living wills at Time 2. It must be noted that attitude towards living wills, was not addressed in the study, however the results indicate that attitudes towards end-of-life care had a direct relationship with signing living wills. Signing living wills include discussing options, either to get information or to inform doctors about living wills. Therefore, it is hardly surprising that positive attitudes towards end-of-life issues had an influence on signing living wills. Older people with stronger attitudes may be more likely to persist (or give up) on attempting to have this discussion. Attitudes are the only component of the TPB to include an emotional component, and it may be that discussing the highly emotional topic of death and dying is primarily influenced by emotional rather than rational factors.

Dying with dignity directly predicted advance care planning. The previous study (Chapter 5) and past research has highlighted the importance of dying with dignity, not wanting to be a burden, wanted to be autonomous, wanting to die a comfortable death and wanting to be treated according to their religious beliefs. However, further research is needed to understand these concepts and why they are so important. This will be addressed in the next study of this thesis.

The results suggest that participants who had discussed end-of-life issues with their doctors at Time 1, were likely to do so at Time 2. Likewise, participants who had signed living will at Time 1 were more likely to do so at Time 2. Several studies have reported independent effects for past behaviour when applying the TPB (e.g. Godin, Valois, & Lepage, 1993; Norman & Smith, 1995, see Conner & Armitage, 1998, for a review). However, at the multivariate level past behaviour did not predict future behaviour. The line of theory and research on predictive value of past behaviour has suggested that the frequent performance of behaviour leads to habit, and once that has been established this habit controls later behaviour without conscious cognitive mediation (e.g. Bagozzi, 1981; Triandis, 1977). Signing a living will is not typically something a person does frequently or habitually, whereas discussing end-of-life issues with the doctor could be something that could be performed more frequently. It is plausible that past behaviour contributed to positive attitude strength and leads to the production of stronger and more spontaneous accessible attitudes and also to higher perceived behavioural control. Past behaviour enriches attitudes and when new information is acquired, the experience makes attitudes stronger. However, when there is no experience there is no basis for the attitude to develop.

Reviews of literature indicate that intentions account for 20-30 % of the variance in social and health behaviours (e.g. Rutter, 2000; Sheeran & Orbell, 1999). Despite the support that intentions predict behaviour, these studies suggest that many people with positive intentions do not succeed in establishing behaviour. The results of the present study suggested that a high proportion had performed the behaviour that they were intending to perform, while a smaller percentage did not perform the behaviour that they had intended to perform. In behaviours which require the co-operation of others, such as discussions or communication, despite intentions a person may not perform the behaviour. Inclined communicators suggested that they did not perform the behaviour because they felt that their doctors did not have time for these conversations. Likewise, inclined non-signers suggested that doctors and families did not have time for these discussions and were unwilling to talk about these issues.

An interesting theoretical development in the recent literature regarding the conceptual distinction between 'goal intentions' and 'implementation intentions' (Gollwitzer & Brandstatter, 1997) explains why some individuals fail to practice healthy behaviours despite positive intentions. Expectancy-value theories have mainly concentrated on goal intentions ('I intend to achieve X'), while implementation intentions ('I intend to perform goal directed behaviour Y, when I encounter situation Z') have been ignored by the expectancy-value approach (Rutter, 2000). The concept of implementation intentions explains why one individual who intends to perform behaviour goes on to do it, while another with the same intentions does not. In the case of advance care planning, where there may not be an urgent threat or risk, older people who were relatively healthy may not perform the behaviour unless they were encountered with illness or disability. Implementation intentions are likely to be particularly effective in the context of behaviours or goals which are complex or where the timing and location for action are uncertain (Rutter, 2000; Sheeran & Orbell, 1999). These conditions may apply to advance care planning.

Additionally, more attention needs to given to situational factors, as intentions may change as the situation or context changes (Ajzen, 1996; Sutton, 1996). Advance care planning, which may be influenced by various situation factors, such as an illness, death in the family. Therefore intentions may change because the context had changed, which may offer some explanation for the gap between intentions and behaviours.

The study had various limitations, particularly with regard to the sample. Participants tended to be quite knowledgeable about end-of-life issues and advance care planning and a large proportion of them had conducted advance care planning previously. A different sample, with less positive or accepting attitudes towards end-of-life issues and those that were contemplating these issues for the first time, would perhaps have yielded a different pattern of results. In addition, the sample that dropped out had less positive attitudes that those who participated in both Time 1 and Time 2. The sample at Time 2, tended to be younger, more educated and of a higher socio-economic status. Despite follow ups, the sample at Time 2 remained relatively small which made it difficult to conduct analysis to delineate the effects of those who had discussed end-of-life issues for the first time and those who had signed living wills for the first time at Time 2. Additionally, some of the constructs were measured by single items, which was not ideal. However, the constraints due to the length of the questionnaire and the age of the sample, made it difficult to include multi-item measure of constructs. Finally, the rational used to include variables in the multiple regressions to predict intentions to discuss end-of-life issues with the doctor and intentions to sign living wills included only the variables that were significant at the univariate level (significant correlations). This analytic approach may therefore have overlooked the effects of variables not included in the model.

6.8 Conclusion

TPB offers a conceptual framework to guide research in future investigation of advance care planning. However the TPB constructs did not function entirely as the theory predicts. The additional variables examined such as dying with dignity proved to be a useful addition to the TPB. Although the variables studied here were moderately effective at predicting intention and behaviour, this study leaves many unanswered questions. This study identified several constructs that are important for older people when making decisions on advance care planning, but this study did not provide an explanation of how these social cognitions are formed, how these decisions are made and what these constructs mean. These gaps will be addressed in the following chapter, where the focus will be processes rather than content.

Chapter 7:

Contextual factors in framing resuscitation decisions and advance care planning: A focus group study

7.1 Introduction

The aim of this chapter was to qualitatively explore the perspective of older people living in the community towards resuscitation and advance care planning, within the framework of the social cognitive approach adopted by the researcher. As suggested in Chapter 4, the use of a qualitative approach in this study was to provide another source of data to complement the findings of the quantitative study reported in the previous chapter (see Chapter 6). Therefore, this study aimed to explore whether the Theory of Planned Behaviour has phenomenological validity. A qualitative approach would help contextualise the way in which older people frame resuscitation decisions and advance care planning, taking into account historical, psychological, social and economic views on these issues. Further, the study also aimed to understand the attitudinal, normative and control beliefs of older people's views on resuscitation and advance care planning by investigating the meaning they ascribe to these concepts. Finally, this study aimed to elicit a variety of opinions of older people who may not be well informed about life prolongation and may not have considered advance care planning.

Therefore, this study addressed primarily the following three research questions

1. What are the issues that older people contemplate prior to making decisions about resuscitation?
2. Why do some older people think about making resuscitation decisions and advance care planning decisions, while others do not?
3. Does the Theory of Planned Behaviour have phenomenological validity in exploring older people's views about advance care planning?

Focus groups were chosen as an appropriate method of eliciting older people's views about resuscitation and advance care planning. Focus groups possess characteristics of participant observation and individual interviews (Madriz, 2000). Owen & Payne (1999) have noted that much of the research on death and dying has used participant observation studies and interview studies. Focus groups involve the simultaneous use of multiple respondents to generate data, which is focused on a particular issue and relatively staged by a moderator (Krueger & Casey, 2000). The method is based on the assumption that people become more aware of their own perspective when confronted with active disagreement from others. The interactional elements of focus groups enable participants to ask questions to each other, as well as to re-evaluate and reconsider their own understanding of their specific opinions. Focus groups have been regarded as a key method of tapping into social norms and social mores through close analytic attention to the process of consensus and the dilemmatic nature of focused debate (e.g. Kitzinger, 1995). It has been suggested that the use of the dynamics of a group discussion is particularly appropriate when studying opinions and attitudes about taboo subjects (Flick, 2002). Seymour, Bellamy, Gott. Ahmedzai & Clark (2002) suggest that focus groups are particularly useful in the study of areas that are little understood by researchers, infrequently discussed in day-to-day life and sensitive in nature, such as end of life care. Focus groups provide a means of understanding people's views about a specific area of enquiry in a non-threatening setting (Morgan, 1988). The little research conducted in the UK on advance care planning on non-medical patients has used focus group methodology (e.g. Seymour et al., 2004; Phillips et al. 2000).

7.2 Method

7.2.1 Participants and Recruitment

Eight focus groups were held with a total of 48 participants from 8 community groups representing a range of older people residing in or near Guildford, UK. Participants were recruited from the following organisations: Age Concern, the University of the Third Age (two groups), the Voluntary Euthanasia

Society (VES), a Catholic church group, a residential home, a day care centre, and the Catenians Association (an international brotherhood of Catholic business and professional men). These organisations were chosen to reach participants varying in education and income level, religion, and level of interest in and knowledge of the topic. The study was advertised with notices and fliers, and with the help of administrators of these organisations (see Appendix 12). Seymour et al. (2002) suggest that when groups 'naturally occur', i.e. when members know each other by dint of some alliance or membership to an organisation, then focus groups serve two purposes, of providing a supportive atmosphere to participants to explore sensitive issues, and also to introduce the researcher to the cultural values of the group.

The study was described as research into the challenges of ageing and medical decision making in the later stages of life (see Information Sheet, Appendix 13). Those interested in participating were invited to telephone or e-mail to obtain more information. Interested participants were sent an information sheet describing the study so that they could make an informed choice about their participation. Eligibility criteria were: 65 years or older, living in the community, English-speaking, and sufficiently mentally competent to participate in a focus group discussion. Eligibility was determined during the initial telephone call where participants were given details about the study. Eligible participants included those who had a terminal or chronic condition but were not currently hospitalised, and those who were recently bereaved. Ethical approval was sought and obtained from the University of Surrey Advisory Committee on Ethics.

Within many qualitative studies, the focus of enquiry is the participants' understandings of a given issue. As any given individual is likely to hold multiple or even contradictory understandings of a particular issue, sampling procedures should attempt to recruit a diverse set of older people rather than a strictly representative sample. The sample may therefore be described as purposive rather than representative.

7.2.2 Focus Group Guide

A semi-structured focus group guide (see Appendix 14) was used to direct discussion on resuscitation and end-of-life care decision making. The guide covered the following issues:

Healthcare challenges of ageing. To build rapport and to involve all participants in the discussion, participants were invited to introduce themselves and explain briefly their reasons for participating in the discussion group. Participants were encouraged to talk generally about the challenges of ageing with respect to healthcare. All participants were invited to discuss these issues in turn, so as to give each the opportunity to contribute to the discussion. When a participant mentioned death, dying, care at the end of life or bereavement, the facilitators asked whether other participants had thought about these kinds of issues and whether they had discussed them with anyone.

CPR and the DNAR order. These topics were introduced with a brief description drawn from BMA documents and a drawing of a patient undergoing CPR. Prompts included asking who should make the resuscitation decision, what factors should be taken into account, and when is the best time to think about and make these kinds of arrangements.

Advance care planning. This topic included living wills, discussing end-of-life issues with doctors, and with family members. It was introduced by asking the group "How can individuals ensure that their dying process is in accordance with their wishes?" Where necessary, the researchers provided a short description of the living will.

Participants were asked the degree to which they would like to discuss these issues with their doctors. Prompts included why they would choose to talk with their doctors, how easy would it be for them, and what problems would they anticipate when trying to have such a discussion. Participants who had not spoken about these issues with their doctors were encouraged to discuss why they had not done so and to identify the barriers to such a discussion. Participants who had spoken with their doctors were asked to offer suggestions for others based on their experiences. The same approach was used to generate discussion about raising end-of-life issues with family members and signing a living will. The legal status of the living will and involving family members were explained to participants. By this point, the group often spontaneously began to debate the pros and cons of each of the methods of advance care planning, including members saying which method of advance care planning would be most suitable for them and the reasons for choosing one method over another.

Debriefing

Finally, participants were asked whether they had any comments on the group discussion, the research project, or any further observations they would like to make. At this stage any questions and queries that participants had about any of the issues raised in the interview schedule were addressed.

7.2.3 Procedure

All the focus groups were conducted either in one of the participants' homes or in Age Concern premises. The same two facilitators (the author and a colleague from the University of Surrey's Centre into Research into Ageing and Gender) ran all the groups. At the beginning of the focus group, participants signed consent forms (see Appendix 15) and provided some demographic details (see Appendix 16). With permission, the discussion was audio-taped and subsequently transcribed verbatim. Participants were assured that all comments would be non-attributable, and ground rules were established to ensure confidentiality. The focus groups lasted about an hour and a half. At the end of the session, participants were given a list of organisations that could provide help, information or counselling, and a condensed form of an information sheet produced by the Resuscitation Council (2002) describing CPR (see Appendix 16). They received £20 compensation for time and expenses.

7.3 Analysis

Data from the focus groups were analysed following the steps of the interpretative phenomenological analysis (IPA) method prescribed by Smith, Osborn & Jarman, (1999), with the aid of the qualitative research computer programme NVIVO. Following IPA procedures, the transcripts were analysed for recurring themes. Themes emerged within individual focus groups and across different focus groups. The process of identifying themes involved various steps. The transcripts were read several times. The analysis of each transcript began with initial thoughts, highlighting themes that were particularly interesting. These were coded with a key word or phrase that broadly captured the theme. These were represented as emerging themes. At this stage, the researcher consulted with another researcher, who had assisted in conducting the focus groups. This second researcher had analysed the data in the same way. The emerging themes were compared and discussed and an agreement was reached regarding their significance. If these emergent themes were repeatedly found across and within focus groups, they were noted as recurrent themes, as they represented shared understanding. Each recurrent theme was then selected for further in-depth, intensive analysis by re-reviewing the transcripts. This was done primarily by the first researcher. Material that was not previously selected was included. At this stage, some of the themes were recoded. The researcher continued to examine the transcripts for connections among these recurrent themes, which were established by considering their context. Groups of related recurrent themes were organised under a master theme. This approach is both phenomenological and interpretative, with an emphasis on themes emerging from the data and the researcher's interpretative engagement with the respondent's text. For further details concerning this analytic method see Smith (1996, 2004).

Interpretative phenomenological analysis has previously been used on individual in-depth interviews, while it's application to focus group data is quite recent (e.g. Dunne & Quayle, 2001; Flowers, Duncan & Knussen, 2000). The use of focus groups in this study raises questions about the appropriateness of using IPA with the data generated. Members of each of the focus groups belonged to a particular affiliated group and often knew each other and were homogeneous in certain characteristics. Hence each focus group could represent a case. In addition, using focus groups could have lead to a focus on working out group dynamics rather than addressng the issues that the focus group was convened to discuss. However, in this case this was not true. For example, the religious groups (church group and Catenians) knew each other as members of their religious group. However their focus was on discussing concerns about topic related issues rather than a preoccupation with interpersonal factors. Participants across the focus group were interested and motivated to discuss the topic under investigation. Therefore, the researcher was convinced that, as individuals, they would not have hesitated to dissent from any views with which they did not agree or identify. Finally, the moderators of the focus groups did not observe any significant impact of group dynamics. This was further supported by the tone and content of the taped material. Therefore, it was deemed appropriate to use IPA as a method of analysis on the focus group data generated in this study.

Interpretations of the themes are illustrated by extracts from the transcripts. In the extracts, (...) indicates that material has been omitted, material in brackets ( ) was added for clarification by the authors, and pseudonyms are used. It should be noted that these themes are not mutually exclusive.

7.4 Results

7.4.1 Participant Characteristics

The number of participants in each focus group ranged from 5 - 7, with a mode of 6. A description of the participant characteristics of the eight focus groups is presented in Table 7.1. In total, 20 men and 28 women participated in the focus groups. Most focus groups included both men and women, except for the Church group (all women) and the Catenians (all men). The majority of participants were under the age of 84 (n = 45, 93.75 %). The majority of participants had completed college (n = 36, 75 %), participants recruited from the Catenians tended to be more highly educated and those recruited from the residential care setting the least educated. The majority of the participants (n =26, 58.33 %) were married or had a partner, while 12 participants (22.2 %) were widowed. Participants from the University of the Third Age (group 2), from the Church and from Age Concern were more likely to live alone. Most of the participants were currently retired (n = 41, 85.42 %), and described themselves as Christians (36, 75 %) and white (n = 47, 83.3 %). Participants from the VES and Age Concern were more likely to describe themselves as having no religion. A large proportion of the participants had no long-term illness (n =31, 58 %), with the exception of participants recruited from the residential care setting. The majority of the participants had not been hospitalised in the past 5 years (n = 30, 62.5 %). Participants from the Catenians and the residential care setting were more likely to have been hospitalised in the past 5 years. All participants described their current health status as fair to good, and no participant described his or her health as poor.

Table 7.1: Demographic characteristics of the participants

		U3A (I)	U3A (II)	Church group (III)	Catenians (IV)	Residential care (V)	Day care centre (VI)	Age Concern (VII)	VES (VIII)
		N = 6	N = 5	N = 6	N = 6	N = 6	N = 6	N = 7	N = 6
Gender	Male	1 (16.7%)	1 (20 %)	-	6 (100 %)	3 (50 %)	3 (50 %)	2 (28.6 %)	4 (66.7 %)
	Female	5 (83.3 %)	4 (80 %)	6 (100 %)	-	3 (50 %)	3 (50 %)	5 (71.4 %)	2 (33.3 %)
Age	65-69	2 (33.3 %)	-	1 (16.7 %)	1 (16.7 %)	1 (16.7 %)	-	3 (42.9 %)	2 (33.3 %)
	70-74	3 (50 %)	-	2 (33.3 %)	2 (33.3 %)	2 (33.3 %)	2 (33.3 %)	2 (28.6 %)	3 (50 %)
	75-79	-	3 (60%)	2 (33.3 %)	2 (33.3 %)	1 (16.7 %)	2 (33.3 %)	2 (28.6 %)	1 (14.3 %)
	80 +	1 (16.7 %)	2 (40 %)	1 (16.7 %)	1 (16.7 %)	2 (33.3 %)	2 (33.3 %)	-	-
Marital status	Single	-	-	2 (33.3 %)	-	-	1 (16.7 %)	1 (14.3 %)	1 (16.7 %)
	Married	3 (50 %)	2 (40 %)	2 (33.3 %)	4 (66.7%)	4 (66.7 %)	3 (50 %)	3 (42.9 %)	4 (66.7 %)
	Separated	2 (33.3 %)	1 (20 %)	-	1 (16.7 %)	-	1 (16.7 %)	1 (14.3 %)	-
	Widowed	1 (16.7 %)	2 (40 %)	2 (33.3 %)	1 (16.7 %)	2 (33.3 %)	1 (16.7 %)	2 (28.6 %)	1 (16.7 %)
Education	Secondary	3 (50 %)	-	3 (50 %)	1 (16.7 %)	6 (100 %)	3 (50 %)	3 (42.9 %)	-
	College	2 (33.3 %)	3 (60 %)	3 (50 %)	1 (16.7 %)	-	2 (33.3 %)	2 (28.6 %)	4 (66.7 %)
	University	1 (16.7 %)	2 (40 %)		4 (66.7 %)	-	1 (16.7 %)	2 (28.6 %)	2 (33.3 %)
Employment	Retired	5 (83.3 %)	5 (100 %)	5 (83.3 %)	6 (100 %)	6 (100 %)	5 (83.3 %)	5 (71.4 %)	4 (66.7 %)
	Part-time	1 (16.7 %)	-	1 (16.7 %)	-	-	1 (16.7 %)	2 (28.6 %)	2 (33.3 %)
Religion	Christianity	6 (100 %)	4 (80 %)	6 (100 %)	5 (83.3 %)	5 (83.3 %)	5 (83.3 %)	2 (28.6%)	3 (50 %)
	Others	-	1 (20 %)	-	1 (16.7 %)	-	1 (16.7 %)	2 (28.6 %)	1 (16.7%)
	None	-	-	-	-	1 (16.7 %)	-	3 (43.8 %)	2 (33.3 %)
Ethnicity	White	6 (100 %)	5 (100 %)	6 (100 %)	5 (83.3 %)	6 (100 %)	6 (100 %)	7 (100 %)	6 (100 %)
	Other	-	-	-	1 (16.7 %)	-	-	-	-
Independence	Alone	2 (33.3 %)	4 (80 %)	4 (66.7 %)	2 (33.3 %)	2 (33.3 %)	3 (50 %)	4 (57.1 %)	2 (33.3 %)
	Spouse	4 (66.7 %)	1 (20 %)	2 (33.3 %)	4 (66.7 %)	4 (66.7 %)	3 (50 %)	3 (42.9 %)	4 (66.7 %)
Health	Good	5 (83.3 %)	4 (80 %)	6 (100 %)	5 (83.3 %)	5 (83.3 %)	5 (83.3 %)	5 (71.4 %)	6 (100 %)
	Fair	1 (16. 7 %)	1 (20 %)		1 (16. 7 %)	1 (16. 7 %)	1 (16. 7 %)	2 (28.6 %)	-
L-T illness	Yes	1 (16.7 %)	1 (20 %)	-	2 (33.3 %)	5 (83.3 %)	3 (50 %)	2 (28.6 %)	3 (50 %)
	No	5 (83.3 %)	4 (80 %)	6 (100 %)	4 (66.7 %)	1 (16.7 %)	3 (50 %)	5 (71.4 %)	3 (50 %)
Hospitalised	Yes	-	2 (40 %)	1 (16.7 %)	5 (83.3 %)	3 (50 %)	1 (16.7 %)	4 (57.1 %)	2 (33.3 %)
	No	6 (100 %)	3 (60 %)	5 (83.3 %)	1 (16.7%)	3 (50 %)	5 (83.3 %)	3 (42.9 %)	4 (66.7 %)

Note: *FG 1: University of the third age, Psychology Group; FG 2: University of the third age, non- Psychology Group; FG 3: Church Group (Roman Catholic); FG 4: Catenians:* brotherhood of Catholic business and professional men; *FG 5: Residential Care setting; FG 6: Age Concern, walkers group; VES: Voluntary Euthanasia Society, S.E. Surrey Branch.*

7.4.2 Interpretative Analysis

The interpretative analysis revealed four overarching and related master themes reflecting the ways in which older people frame resuscitation decisions: Older people's attitudes towards death and dying, the attitude of others towards death and dying, older people's perspective on quality of life and the involvement of others in the decision making process. Within each master theme, several more specific recurrent sub-themes were identified to contextualize older people's views of the resuscitation decision making (presented in Table 7.2), will be discussed. While these themes are presented as four discrete themes, it should be noted that they are interrelated.

In general, most participants were comfortable and openly discussed their views on these issues. In each of the groups, there was a variety of differing attitudes, which made for interesting conversation and debate within the group. On a very few occasions, a participant in the group seemed slightly uncomfortable with the discussion and on one occasion, a member of the group became emotional and had to be escorted out by the second facilitator. It must be noted that even though participants were not questioned about their personal beliefs about their resuscitation decisions, a substantial number of them did consider their own personal factors and experiences during the discussions.

Table 7.2: Master themes and sub-themes

Master themes	**Sub-themes**
Attitudes towards death and dying	Age and accepting attitudes
	Illness and mortality
	Stoicism and acceptance
Attitudes of others towards death and dying	
Value for quality of life	Medical condition
	Physical and mental function
	Age and ageism
	Being a burden
Control and involving others	Autonomy
	Involving the doctors
	Involving the family

7.4.3 Attitudes towards death and dying: confronting mortality

This broad theme addressed participants' attitudes toward death and dying and the effect these attitudes had towards advance care planning. In general, the more positive or accepting the individual was towards their own mortality and towards ageing, the more likely they were to think about deliberating about resuscitation and advance care planning. In contrast, the anxiety of confronting the reality of death or 'denial' makes it difficult for an individual to even contemplate issues of resuscitation and advance care planning. Attitudes towards death and dying worked at two levels. Firstly, influencing whether older people even contemplated whether resuscitation decisions and advance care planning should be considered. Secondly, their attitudes towards death and dying directly influenced whether they conducted advance care planning.

> *TV: '... you shook your head'*
> Margaret: *'I haven't talked about it to any of my children. Well I haven't really thought about it. I had a complete knee replacement about seven years ago, but even then it didn't occur to me to say anything. You know, the popular phrase at the moment is 'I am in denial'. So maybe that is why it is? I am very proud and independent. Perhaps I just don't want to look at it. Well, I don't really know. It is just something that I never think about'.*
> Heidi: *'No, I don't think about dying. I have not made my will. If you don't think about it, you don't get there do you (laughs), all the time you keep going'.*
> (Day Centre)

These members of the day care centre regarded not thinking about death and dying, as a way of avoiding death and a feeling of maintaining their independence. Others felt that thinking about these issues was important and an acceptance of one's mortality influenced the decision to conduct advance care planning.

> Audrey: *'I think talking about dying is important and the sort of care you want, of course that depends on whether you think about death. You need to make your intentions known, I think it's very important that you communicate ... or have it written down in the will. But I think that comes with acceptance of your mortality and the fact that you are ageing'.*
> (Age Concern)

Participants offered explanations as to why some people are more likely to think about these issues than others. In other words what are the precursors of attitudes to death?

7.4.3.1 Ageing and mortality

Accepting that one is growing older led people to accept their mortality. Jack from the VES said '...maybe because you get older and you automatically think that your life is shorter, yeah. ... then you automatically think'. While Helen from the Age Concern admitted 'I don't really think about death and dying very often and I don't very often think about my age'. The experience of ageing gets people to think about their own death. Growing older is also associated with being more involved in other people's mortality, seeing family members and friends die leads to people thinking about their own mortality. Participants in the Church group had very accepting attitudes towards death and dying. Both these women, who were widows, elaborated:

> Edith: *'It is when you find yourself deeply involved in other people's mortality, parents, grandparents, wife. I now have a mother-in-law at this stage, so I have been giving it some thought'.*
> Suzan: *'I attend so many funerals of friends and you know, you can sort of visualize yourself when it comes to your day'* (Church group)

7.4.3.2 Illness and mortality

Personal experiences with illness led people to think of death and hence make arrangements for their own end-of life care. Older people who were healthy tended not to think about their own mortality. The conversation between Sarah and Jane from the University of the Third Age illustrates that illness makes people think about their own mortality, while when healthy individuals do not contemplate these issues.

> Sarah: *'I think about dying. I've had 2 lots of cancer and I always think that perhaps it will happen to me'.*

> Jane: *'I don't think you can actually be well and be thinking those kinds of things. You know, you don't go around wondering what you're going to do if you get ill. It's the last thing in your mind'.*
> ...
> Jane: *'I don't think, I think too much about death. As I see it I am very healthy at the moment and if I go downhill, it won't just be tomorrow, it will be ages to go yet so you have to be prepared to alter your ideas. The older you get while you feel healthy, you do everything, you know, you don't think about the next stage.*
> Suzan: *'Obviously we are getting nearer and nearer to death, and it is no good pretending we are not, but I think it is quite important we organise ourselves to let our relatives know exactly what we feel about things when it comes to perhaps making a decision'.* (University of the third age, II)

The more serious the illness, the more likely older people are to consider issues of advance care planning, while others with non-serious conditions did not consider advance care planning.

> Helen: *'I think you don't really start thinking about your health, until something happens, which happened to me 3 years ago (had a heart attack 3 years ago). I think it suddenly strikes home. You think 'Oh yes, I am getting old and I have to starting thinking about things (death and making arrangements).'*
> Doreen: *'I can stop and think about it, particularly with the news I have at the moment (going for a eye surgery) and I think 'Isn't it strange, I shan't be here in 20 years time, the world is going to go on without me and I shan't be here' and I switch off. I think we are very good at switching off'.* (Age Concern)

An explanation was offered as to why older people who were not seriously ill don't think about their own mortality.

> *Jane: 'I think that all human beings have got a sort of built-in protection against the knowledge that we're all going to die, because if from the moment you realised that you were going to die, it played on your mind all the time, you'd have no quality of life ... As you get older you don't know the future, there might be 5 minutes or 15 years, you've no idea and this sort of built-in attitude just keeps you going, because we've got this self-protection against (thinking about it)'.* (University of the third age, II)

7.4.3.3 Stoicism and acceptance

The stoical approach or a belief that 'God determines everything for the best and that virtue is sufficient for happiness' leads to acceptance of death, which makes advance care planning easier to conduct.

> Gayle: *'Well its part of life, isn't it? I think if you're matter-of-fact about it, matter-of-fact with your friends and your relations. Fine, it doesn't worry you, it doesn't worry them, and it's part of life.'*
> George: *'The situation is going to come to all of us anyway, we all have to kick the bucket one of these days, whether we do it today or do it tomorrow.'* (University of the third age, I)

This stoicism often lead to a fatalistic approach to decisions about life and death, which results in not wanting resuscitation or the decision regarding life prolongation not being made.

> Edith: *'I have always said when my time comes no one should resuscitate me. I want to just drift away and when God wants you home he wants you home'.*
> Suzan: *'I think you have to go with the flow ... whatever supposed to come to you, comes to you and its no good you fighting against it, because if it happens to you, it happens to you, so I think as far as we concerned, because we believe in our religion ... we know whatever happens to us is supposed to happen'*
> Edith: *'No, I think there's a time to be born, and a time to die and whatever we try to do is not going to intervene, when you're put on this earth for a certain amount of time'.* (Church Group)

7.4.4 Attitudes of others towards death and dying

Perceptions participants had about the attitudes of their families towards death and dying influenced the decision to discuss resuscitation decisions with them. Older people had various perceptions about how their families would react to a conversation about life prolongation. It was thought that some families would be more supportive to this conversation, while others would not like to talk about these issues, using humour as a defence. Gender differences in families' attitudes towards discussing these issues were also highlighted: with male members of the family considered to be less willing to discuss these issues. These beliefs about families' attitudes towards discussing end of life care had an influence over whether older people discussed their resuscitation wishes with their family members.

> Diana: *'It all depends on your children. Some have got different attitudes than others. Some of them have said 'Oh Mother, don't talk about that!' Another one would say 'Just shoot'. It depends on your children; some don't want to talk about it'.* (Residential Care)

A belief that the family would have accepting attitudes and accept their decision would result in older people initiating these conversations.

> Emily: *"I think if I were to say to them "I don't want to be resuscitated and I want you to sort of make sure the doctor knows", I think they would just sort of say: 'all right mum, yes OK' and they would probably make a joke of it."* (University of the third age, II)

> Heidi: *'If I try and bring up the subject with my son, he won't discuss it. He'll says 'oh mum, you'll live to be a hundred' but I have discussed it with my daughter in law. He doesn't like to think of me going.'* (Day Care Centre)

Various explanations were offered to understand families' (especially children's) reactions to conversations on life prolongation.

> Bob: *'I think it would be very difficult for a younger person to actually appreciate how an older person feels and appreciate being ill and being infirm.'* (University of the third age, I)

> Diana: *'People find it upsetting to talk about (these issues) don't they? Especially the younger people, they don't like to think of their parents or uncles and aunts dying, they want them to be there. I probably didn't think about it when I was young'.* (Residential Care)

> Suzan: *'I think it must be a very hard to imagine your parents dying. Surely they wish that something could be done to hang on'.* (Church group)

7.4.5 Value for quality-of-life

This broad master theme encompassed factors participants took into account when evaluating quality of life for themselves or others. Quality of life emerged as the central value underlying the dilemma of whether or not to apply a life-sustaining medical technology such as resuscitation. One of the Catenians highlighted the importance of assessing QOL, as well as the dilemma that people face when making resuscitation decisions: *'I think it's very difficult to judge when somebody has a quality of life, which isn't worth living. I don't think one can make judgements like that. On one hand you have to let nature take its course and on the other if there are techniques, machines available I think we should do something. Ultimately I suppose the decision has to be made but it needs to be made very carefully'.*

Resuscitation would be chosen only if the individual was enjoying an acceptable quality of life before CPR or could be reasonably expected to have an acceptable quality of life after CPR. However, the CPR decision became difficult when the individual's pre-CPR quality of life was not known, and/or the chances of survival and quality of life post-resuscitation could not be predicted. The definition of an acceptable quality of life in this context was an individual matter and therefore difficult for others to determine. However, quality of life was influenced by the medical condition of the participant, whether an individual was physically or mentally disabled, age, and whether the participant felt that they would be a burden on others.

7.4.5.1 Medical condition

Judgements of quality of life before resuscitation were based in part on the individual's health status. When an individual had a terminal illness they should not be resuscitated, but resuscitation should be attempted for acute conditions (such as a heart attack) in an otherwise healthy person. From this perspective, quality of life was defined in terms of how much more "good" life an individual could expect. In addition, a person's previous health status was a basis for predicting their response to resuscitation: those who are iller are less likely to survive CPR or to have a good quality of life after CPR.

> TV: *'What are people's thoughts about resuscitation?'*
> Jean: *'My idea of resuscitation for someone who has had a heart attack is different with someone who is terminally ill. If someone has had a plain heart attack they should try because if they resuscitate they could live*

> *longer. But if you have a terminal illness the rest of your body is not going to be able to cope with it.'*
> Diana: *'Well I think it is a very difficult subject...because if I were very seriously ill and I was going to be terribly disabled physically or mentally if I lived much longer, I would not want resuscitation. The trouble is you can't really decide these things in advance ... Some people think 'life at any cost', must keep people alive, and I don't subscribe to that'.*
> (Residential Care)

Using medical condition as a basis for the resuscitation decision is an attempt to conceptualise and make this difficult decision easier. Resuscitation may not result in acceptable quality of life post-CPR. Hence, for a terminally ill person, the risk of an attempted resuscitation is not worth taking. Similarly, for a person with much lower present quality of life (which limited their daily activities) compared to the past, life-prolongation is not attractive.

> Mrs Adams: *'I feel, I don't want resuscitation, I am blind and because I can't cope any more.'*
> (...)
> Mr Adams: *'Well everyone has their own idea, but as I said, we have discussed it and we know exactly where we stand, the children know where they stand. It is in their hands more than anything. I mean, she, up to what, twelve years ago, maybe a bit longer, no-one could catch her... That (is) what she used to be like. But her life now is sitting on her bed or in the wheelchair. She can walk round the flat with a frame to a certain extent'.* (Residential care)

7.4.5.2 Physical versus mental impairment.

One important distinction for evaluating quality of life was whether an individual had physical or mental impairment. Mental incapacity, which was associated with being unable to communicate and having limited cognitive abilities, was considered much more threatening to quality of life. Under the situation of having Alzheimer's disease or senile dementia, the DNAR order was preferred. Assessment of perceived quality-of-life post-resuscitation was also taken into account when framing resuscitation decisions. Resuscitation was not wanted if it would leave them a 'vegetable' or a 'cabbage' (either physically or mentally) and this was not a 'life worth saving' because they would not emerge as the person they were before the attempted resuscitation. These extracts also indicate that older people were aware of and well-informed about the potential for adverse effects of a resuscitation attempt and these factors did come into play when making decisions regarding resuscitation.

> *Emily: 'I think a lot depends on what sort of person you're going to be when you emerge again. If you're going to be as alert and as able as you were, then it was a thing well done but if you're going to be severely disabled either mentally or physically then perhaps a little more thought is necessary'.*
> *(...)*
> *Anna: 'Well I think you need somebody who actually knows what you're going to be like when you have been resuscitated and if you're going to be an OK person then let's do it but if you're not just leave it'.*
> *(...)*
> *Emily: 'Well, as I said I'd like, if I felt I was going to be a cabbage afterward it's better, you know, to go quietly but if I felt I was reasonable, I don't say perhaps not as good as I used to be but reasonable mentally etc, then I'd want to carry on'.* (University of the Third Age)

A variety of opinions were expressed with regard to assessing when it would be reasonable not to resuscitate. The general sentiment was a preference to die a natural death, when mentally or physically unfit. However, assessment of this was difficult.

> John: *'Yes, I think I agree with what David says, it's the worry you might develop senile dementia, more in my case than cancer, 1 in 3 chance of getting cancer but it's worrying if old age makes you mentally affected I think.'*
> David: *'Or if we're dying from cancer, I certainly hope that I would be looked after properly medically and I wouldn't want anybody to bump me off because they decided that my life wasn't worth living.'*
> ...
> Charles: *'That's what I meant earlier, I wouldn't want people not resuscitation me if my brain was still functioning, ticking and especially if I was able to communicate, whether I was totally paralysed or no., I certainly wouldn't wish it but obviously if somebody had suffered mental, severe brain damage and were never going to recover then it's a bit pointless keeping them alive, and I think one would have to face up to those circumstances'.* (Catenians)

7.4.5.3 Age and ageism.

Age was introduced as a basis for making a judgement about quality of life. One position was that younger people's quality of life was intrinsically more valued than older people's.

> Mary: *'Both my husband and I have agreed that we have no wish to be resuscitated. We're both in our 80s and feel that we've had very good life and would not wish to be resuscitated to have a very limited life'.*
> Heidi: *But I think, if you get like you say 70's and 80s, is to let the person go.*
> John: *Oh goodness me!*
> *Harry: (laughs) 'well, it depends how you feel, if there's a chance you'll survive another few years, but whose to know? I mean I think it's far better to try and save a younger person'.*
> *(...)*
> Margaret: *'I should think in his 30s, that's rather different from if you're in your 80s and you've had your life and a lot of your relatives have gone, so you have a very limited existence.* (Day Care Centre)

However, chronological age did not necessarily indicate poor quality of life, and too much emphasis on chronological age was seen as ageist. Janet from the Church group elaborates: 'And they've just had a heart attack, you can't turn around and ignore it and say he's an old person. I mean I told you it's a different matter if somebody has been sick for years and years, it's a different matter'. One member of the Residential Care group said: 'And another thing that gets me, if you are over 70 'Geriatric patient'. Now is that for all people over 70, they are not all geriatric?'

7.4.5.4 Being a burden

Being a burden to one's family or to society indicated poor quality of life. The perception of burden was attributed to the breakdown of the family, where younger family members no longer had the obligation or responsibility to look after their older relatives. In comparison, in continental countries and in the past the family had obligations to look after their older relatives. Older people felt that contemporary society in Britain did not encourage younger family members to take on responsibilities to care for an ageing relative. Others however argued that these were not reasonable expectations to have from their younger generations.

> TV *'Have you ever thought about what you would like in terms of resuscitation?'*
> Ruth *'...So then my husband and I discussed it. Well I still felt 'Yes' I would prefer it. My husband has gone the other way because he has had four strokes and has come out of them okay. He has said 'No, I wouldn't because I don't want to be a 'vegetable'. He is frightened if he has another one and is resuscitated he is going to end up in a wheelchair or be a 'vegetable' and a burden, whatever, and he has said 'No way do I want to be resuscitated.*
> ...
> Audrey: *'...even if you do have a very good family indeed, which I certainly have, there is still this anxiety that when you can no longer look after yourself what are you going to do?'*
> Alan: *'If you can maintain the health you have, you are not going to be a burden to anybody'.*
> Frank: *'But I think when you become a burden and you are not really able to do much for yourself, I mean the essential thing to me is to keep your dignity'*
> ...
> Helen: *'...as you have said on the Continent, they look after their kin much more in their family. I think this is one of our biggest problems that we have lost families completely in this country. Some of us are lucky, but generally speaking families are something that, you know, they go. And there isn't always a hold. ...we grew up with the feeling that you didn't leave your family. You didn't have to concentrate on them, but you were responsible for them at some point maybe for keeping or taking care of your older relatives'.*
> Doreen: *'It was always understood that one's grandmother or grandfather would always end up living with somebody'.*
> Helen: *'I am not saying that is how I would want to see it, no. But at least with some sort of sense of responsibility '.*
> Audrey: *'I think I would long to have those expectations of the children, I really do'*
> Doreen: *'No, I don't think you expect it'.* (Age Concern)

A member of the VES summed up the discussion as follows "...a quality of life that enables sufficient health and enables you to be independent, I think this to me is one of the very important. You not want to become dependent, you do not want to be taken into care and institutionalised, that you want to be in charge, in command of your own life for me is very important."

7.4.6 Control and involving others in the decision making process.

In general, personal autonomy or control was an important issue for older people conducting advance care planning. Those who valued autonomy and wanted control over the decision making in later life were more likely to conduct advance care planning. However, there were concerns about the risk of losing individual autonomy regarding resuscitation. Participants observed that the decision could be out of control because at the time these decisions are made, they could be unconscious, too ill or incapacitated. Signing living wills and wearing bar codes as indicators of personal preferences were associated with retaining control over the dying process.

> *TV: 'So, who would make this decision?'*
> Carol: *'I'd like to make the decision. But how could one do it, if you were unconscious?'*
> Diana: *'...I've given my doctor a copy of my living will.'*
>
> ....
>
> Cathy: *'I'm bewildered. I mean if I'm not capable of deciding for myself I don't know what happens.'*
> Cathy: *'The thing is if you have, if you're taken ill in the street or something, they're just going to resuscitate you and we have no control over that, have we? We can't do anything about it.'*
> Carol: *'I mean what if you get taken to the hospital as an emergency and you are unconscious do they look at you and say: 'old' and then they'd say, 'leave it'?'*
> Jack: *'It is a difficult one (it depends upon the) circumstances (that) could occur. Funnily enough I was just thinking about bar codes know what our wishes were.'*
> Carol: *'Or something round your neck, like diabetics or whatever.'*
> Jack: *'I mean it can be simple, a plastic thing like the dog has out on the street.'*
>
> (Voluntary Euthanasia Society)

However, they highlighted that these decisions were often outside their control and accepted that advance care planning, or making decisions about resuscitation in advance was not always appropriate: 'I don't think you can actually make decisions because we don't know what tomorrow will bring' (University of the third age, I).

The need to enlist the help of experts or loved ones to make this decision was expressed. The groups illustrated a diversity of views. Resuscitation should be a "medical decision" based on a "professional" and "objective view" (Catenians). "The only people it concerns is you and your family" (Residential Care). "I would trust my family absolutely; I would leave it (the decision) to them" (Church group). "Well, I think it should be only the patient's choice" (Day Care Centre).

7.4.6.1 Involving the doctor

Despite medical professionals having the ultimate responsibility for the resuscitation decision and being most equipped to make such decisions, they were seen as biased towards using life-prolonging technologies. "... all the time there's a glimmer of hope, you've got to prolong life, I mean that is the doctor's oath isn't it, they must prolong life and if there's a chance you've got to do what you can" (Church Group). The Hippocratic Oath ('I will keep them from harm and injustice') binds medical professionals and this makes it difficult for doctors to make decisions on resuscitation as they are bound to preserving life. Doctors were "afraid of letting it (death) happen" indicating that death was looked on as failure in medical practice: "I've always been told that it's a black mark against them (doctors) if they lose a patient, so one wonders if it comes to the point they automatically bring you round. I think that worries me" (Voluntary Euthanasia Society). Accordingly, involving the doctor in the resuscitation decisions was likely to swing the balance in favour of resuscitation. Leaving the decision to the doctor can be perceived as not having control over the decision.

7.4.6.2 Involving the family

Despite the family not having legal authority in the decision making process, best practice recommends that the family be consulted, and they should make decisions according to the patient's "best interest". Participants perceived families as able to make decisions on the individual's behalf, and felt their involvement would increase the likelihood that a person's wishes were adhered to. Therefore they are more likely to feel like they are in control over the decision.

> Jane: *'I'd rather trust my family to know exactly and mine do, I have told them so many times and I would rather that than a doctor.'*
> Jean: *'Personally I would rather my family know what I want to do. I mean, you know, my notes might get muddled up with somebody else's or it might be a new doctor'.*
> Sarah: *'I'd rather trust my family to know exactly and mine do. I have told them so many times and I would rather that than a doctor. You know, I see what you mean exactly, perhaps if you didn't have any relatives but I could just imagine it being me.'*
> *Jane: 'I trust them (my family) absolutely, I would leave it to them. If you've got a family who you know you can trust, you can say: "look, I leave it to you but you know my feelings, I don't want to be a vegetable but if it's kind of possible I might get over it, resuscitate me.'*
> (University of the third age, I)

However, another view was that older people should decide for themselves without involving the rest of the family.

> Edith: *'Well I don't think I would burden my family, but once I had made up my mind and say right I'm having this done...'*
> TV: *'Why not'*
> Edith: *'Because I don't think it's fair.'*
> Suzan: *'I'm very close to my family, and I know what I want, so I don't even have to tell them.'*
> Edith: *'I don't think it's necessary.'*
> Suzan: *'I'm very close to my family, but I certainly don't think it's necessary to discuss these things with them.'* (Church Group)

Although some viewed the discussion with family members as an unfair burden on them, a participant from the University of the Third Age observed that informing a family member could be a relief for all concerned: "I told my nephew, and he said: 'I'm so glad you've told me. Because if you hadn't, I'd have moved heaven and earth to keep you alive'. I mean, if you're the heir so to speak, you've got to do everything even, you know, unless you've got written (living will) or been told by your family member". From yet another perspective, it was assumed that the family could be relied upon to know a person's wishes without having an explicit discussion.

> *Suzan: "I'm very close to my family, and I know what I want, so I don't even have to tell them".*
> *Edith: "I don't think it's necessary".*

Suzan: "I'm very close to my family, but I certainly don't think it's necessary to discuss these things with them". (Church Group)

Some viewed the conversation with family members as an information-giving exercise rather than a discussion. Therefore, the decision to attempt resuscitation or forgo treatment was theirs, and informing family members was a way of ensuring that their decisions were adhered to at the end-of-life and in the event of incapacitation.

George: *'The decision is in my own hands irrespective of what the children might say afterwards.'*
James: *'I agree I think it should be your decision, its rather like your old car isn't it, it fails the MOT. And I think it should be your decision and I think you should tell your children or discuss it. I personally I would decide myself and say to them 'well, here we are, here's my ticket'.*
George: *'Discussion? If you want a positive input you have to tell the children, because it's such a hurtful subject I find with my children, that they don't want to talk about it.'* (Catenians)

Finally, practical barriers, such as dispersal of family and lack of opportunity often prevented family members from being involved in advance care planning. Due to the sensitive nature of this conversation, they should be conducted face to face and required time and an appropriate environment.

Jude: *'I think the dispersal of the family makes it more difficult, I particularly felt that it was more difficult for me to have this discussion because the opportunity doesn't arise.'*
Ivy: *'Yes, it isn't something I would talk about on the phone. I would need a face to face in order to talk about this. I would need to have an occasion, and then it is usually very busy and noisy.'* (University of the third age, II)

7.5 Discussion

Despite the highly sensitive nature of the topic, the focus group methodology yielded a diverse set of views on the resuscitation decision and related issues. Guided by IPA and a social cognitive framework, the interpretative analysis of the transcripts identified four master themes that described four broad principles that participants believed should be used when making resuscitation decisions: Attitudes towards death and dying, attitudes of others towards death and dying, the appraisal of quality of life and control, and involving others in the decision. Each of these principles encompassed various recurrent sub-themes to explain the ways older people frame resuscitation decisions and advance care planning.

Older people's attitudes towards death and dying often precede the actual cognitive processes involved in making resuscitation decisions. Participants who were contemplating making decisions on resuscitation and/or decisions on advance care planning had accepting attitudes towards their own mortality, while participants who were not contemplating making these decisions either worried about their own death or were in 'denial' about their own mortality. These interesting results suggest that there is often a step prior to older people evaluating the cognitive processes involved in making the resuscitation decision, which social cognitive models such as the Theory of Planned Behaviour fail to take into account. However, other social cognitive models such as the Transtheoretical model or the stages of change model (Prochaska & DiClemente, 1982) suggest that prior to contemplating the issue (such as making a resuscitation decision or the decision to conduct advance care planning), individuals may go through a stage of 'precontemplation', where they do not intend to make any changes. At this precontemplation stage, an accepting attitude towards death and dying may lead to a person further evaluating their values towards resuscitation, and make decisions to conduct advance care planning. However those with death anxiety or those not willing to think about death and dying, fail to reach the next stage of evaluating their beliefs about resuscitation and advance care planning.

The idea of 'successful ageing' with its emphasis on a positive attitude towards life in order to maintain life satisfaction in the midst of losses and illness (Wong, 1989), does not allow much room for thoughts about death and dying. Particularly relevant to a young-old cohort, whose emphasis is on maintaining physical health and physical activities, an attitude of preoccupation with mortality and worries about death and dying will rob one of the joys of living. Therefore, for some it was easier to carry on living and not to think about death. However, when old age encompasses illness and loss of peers and family, it reminds older people about their own mortality. Illness is viewed as the grounds for seeing oneself as "really old" (Williams, 1990) and this is the time in which individual's discover the transcendental meaning of life and death (Wong, 2000). This may suggest that it may be inappropriate to consider advance care planning for those who are not ill. However, the results suggest illness and death in the family, an accepting attitude towards ageing and a religious attitude were precursors to an accepting attitude towards death and dying. Therefore for a cohort that was increasingly facing the death and illness of their generation, these thoughts were not inappropriate.

However, some participants who were resistant to confronting the realities of their own deaths, did not think about, discuss or plan for illness or make decisions on the use of life prolonging medical technologies. Hence, it must be acknowledged that a pre-requisition of the resuscitation decision making process is that people need to confront the reality of their own mortality and have accepting attitudes towards their death.

Participants' perception of their families' attitudes towards death and dying and the resuscitation decision influenced their decision to conduct advance care planning. In other words, these subjective norms influenced their decision making planning. The behaviour in question involved communication and often directly influenced the family as they were the ones left with the 'burden' of decision making. Communication about advance care planning infringed on sensitive issues and made family members consider their own mortality or the mortality of their loved ones. Participants perhaps did not want to involve their loved ones as a way of protecting them from confronting these issues, and hence justified their non-involvement by suggesting that family members did not want to be involved. There is no past research conducted in the UK, so far as the author is aware, on the views of family members about their involvement in the resuscitation decision, to which to relate the present findings.

Participants suggested that decisions regarding resuscitation should be made by taking into account quality of life. However, the essential dilemma underlying quality of life as a guide to resuscitation decision making is that quality of life may be unknown or unknowable, particularly during advance care planning. CPR offers the advantage of prolonging an acceptable quality of life, but this must be weighed against the disadvantage of prolonging or creating an unacceptable quality of life. Participants developed various positions on the definition of acceptable quality of life. Important elements of this definition were the individual's current state of health, how it compared with past health, and the extent of mental versus physical incapacity. These individualistic recurrent themes were considered in conjunction with two recurrent themes originating in societal attitudes towards older people and their care. One theme reflected the societal value placed on youth, with younger people being considered more worthy candidates for CPR than the very old. Another theme reflected the societal problem of older people being a burden on the younger generation, indicating that CPR should be withheld if the person would become a burden.

The themes that emerged confirmed past research. Consistent with past research, participants in this study considered health-related assessments of quality of life – present heath and physical & mental incapacitation, when making decisions about life-prolongation (Carmel & Mutran, 1997; Cicirelli, 1997; Ebell et al., 1990; Landon, 2000; Phillips & Woodward, 1999). In this respect, both older people and their doctors use the same principles to make resuscitation decisions (de Vos, Koster & de Hann, 1998; Stoddard, 1998), although they may hold different positions with respect to those principles. Older people take into account not only physical and health related concern about quality of life but also emotional, psychological and social factors when making decisions regarding resuscitation and advance care planning. Consistent with past research, the results also suggest that older people's assessment of quality of life also include psychosocial factors such as age (e.g. Gunasekera et al., 1986; SUPPORT, 1995) and burden (e.g. Schiff et al., 2000; Seymour et al., 2004).

The essential dilemma underlying the principle of involving others in the decision is that involving others endangers individual autonomy. In a society that values individualism and freedom of choice and in the context of the high value now placed on patient-centredness within the UK Nation Health Service, the resuscitation decision should be made in advance by the patient. Therefore, it is recommended that people discuss this and related decisions about end-of-life care with their families and doctors. Such discussions are difficult, even when the person in question is in good health. Involving doctors in this discussion provides professional expertise and leaving the decision entirely to the doctor is one way out of the dilemma. However, the professional commitment to maintaining life, perhaps at almost any cost, could run counter to the high value placed on quality of life as a basis for making the decision. Involving one or more family members places a burden on them. One solution is for the individual to arrive at the decision independently, thus removing the decision making burden and threat to autonomy, and only involve the family or the doctor by informing them of the decision, rather than discussing it with them. Another solution is to believe that other family members know one's wishes without explicit discussion, however this may make it difficult for family members to act in their best interests.

Participants saw a clear role for 'family veto' to resuscitation decisions and wanted their families to act on their behalf. The concept of surrogacy decision making for patients who are too ill to make an informed autonomous decision about their own treatment is different in the United Kingdom and the United States. In the US, healthcare proxies are present and clinicians have a legal obligation to consult with the designated surrogates before making decisions. In the UK, no such legal right to healthcare proxies exists (Doyal & Wilsher, 1993; Stewart, Spice & Rai, 2003; Seymour, 2000). Recent guidelines on end of life decision making from the British Medical Association (2001) encourage the involvement of relatives to aid the clinician to act in the 'best interest of the patient' by informing them about the capacity to benefit and quality of life of the incapacitated patient. Some participants acknowledged that losing a loved one is a difficult process and the bereavement at the ultimate loss of the older relative can be made easier, if family members felt that 'everything was done' for the patient concerned. Often, participants construed the decision making process as being a burden to family members, as they could feel that agreeing to a DNAR was condoning the death of a loved one. However, others thought that making wishes known and discussing life-prolongation with relatives could alleviate the burden of the decision making process.

Social cognitive models, such as the Theory of Planned Behaviour have suggested the importance of perceived behaviour control. The previous study (chapter 6) suggested that older people were more likely to intend to perform advance care planning when they felt that they had control over the behaviour, while perceived behaviour control did not have an effect on actual behaviour. This study provides some explanation for the results: those who valued autonomy or wanted control over the final stages of their lives, were more willing to perform the behaviour, while for others deferring this decision to doctors and family members was a way of avoiding thinking about these distressing issues.

In addition, this study helped contextualise how older people handle decision making in a realistic, dynamic and complex environment and given that these decisions may involve considerations that occur prior to the actual decision making process. Most real-life decision making is bound by a social context which has an effect on individuals even contemplating thinking about the task in hand. This study took into account contextual factors such as living in a 'Death denying' culture and more recent trends towards a more accepting attitude towards death- 'Right to life' movement.- which influence resuscitation and advance care planning decisions. Further, older people's views about being a burden and ageism also impacted the decision making process.

In addition, by including focus groups composed of such different kinds of people the different contexts for end-of-life decision making were explored. Thus, the religious groups (Church group and the Catenians) revealed the influence of a religious context, the University of the Third Age revealed the influence of a more educated and academic context, and the residential care group showed the influence of being in poorer health. Socio-economic diversity was represented by including members of a day centre (lower SES) and Age Concern (higher SES). Finally, members of the VES revealed the influence of those who had thought extensively on these issues and were highly knowledgeable about advance directives.

To some extent, the present study sheds light on inconsistencies found in past research over whether or not patients favour resuscitation (e.g. Hill et al., 1994; Liddle et al., 1994; Morgan et al., 1994; Schiff et al., 2000). The present findings suggest that there is a diversity of views because of the different weights given by individuals to the principles by which this decision is made. Non-representative sampling, such as recruiting participants from particular hospital wards or outpatient clinics, may inadvertently introduce a confound with the value placed on one or more of these principles. A useful direction for future research would be to determine the degree to which the various relevant parties to the decision, including doctors and family members, use the same principles as those identified here. More effective discussions will occur where all parties are using similar principles, even if they hold different positions with respect to those principles.

The principles that emerged from these focus group discussions may prove useful for older people when framing discussions about the resuscitation decision and related issues of end-of-life care. They could be presented as a series of questions for people to answer to determine their own definition of acceptable quality of life and their own wishes regarding the involvement of others. Because of the nature of the resuscitation dilemma, it is all too easy to be unable to come to a decision and to avoid discussing or thinking about it. By developing a position with respect to the underlying principles upon which the decision rests, the decision itself may become clear. This would also allow doctors and family members involved in the decision to gain a perspective on the basis upon which these decisions were made, which could inform their decision making for this person in the future, should this become necessary.

It should be noted that our findings and interpretation are limited by our inability to evaluate the attitudes of those who refused to participate in the study. It may be that those who did not participate in the study held the belief that death is a very distressing subject, and that such a group was not represented in the study. In addition, the sample represented a rather young group of older people who considered themselves healthy and had no terminal illness. It is possible that views would be different if these older people were older, closer to death and/or living with a terminal illness. More research on such groups, including ethnic minorities and a frail older people, is needed and their views may be different.

More importantly, culturally rooted reluctance to anticipate death and end of life care may lead to difficulties in framing and opening these discussion and anticipating resuscitation decisions. Hence more research needs to be conducted on these issues in order to understand older people's wishes for life sustaining treatment. Such studies might encourage more public debate and thus lead to the development of appropriate societal mechanisms and policies for end of life care management.

7.6 Reflection

The centrality of the researcher's subjectivity means that traditional criteria for evaluating research quality (such as reliability), which are based on the assumption of researcher's objectivity and disengagement from the analytic process, are inappropriate when assessing this study. An era of involvement in the research process has replaced the era of objectivity in qualitative research, thereby acknowledging that the researcher's openness and reflexivity to the research is part of the research process and no research is value free. Reflections on the actions and observations in the field, their impressions, irritations, feelings and so on, become data in its own right, forming part of the interpretation (Flick, 2002).

Such an analysis involves a high degree of subjectivity as it is based on the researchers' interpretative frameworks. This research is shaped by different dimensions of difference which permitted relations between researchers, the researched and the research topic. The focus groups were conducted by me, a 25-year old, female, Indian, student of health psychology and a 60 year old, male, British, sociologist from the Centre of Research into Ageing and Gender (CRAG). In this study, it was hoped that the researchers would be sensitized to different aspects of the data due to their respective different interpretative positions in terms of age, gender, ethnicity and professional background. Typically, in theoretical approaches to "othering" or representing members of groups to which we do not ourselves belong, the majority represents the minority (Wilkinson & Kitzinger, 1996). However, my ethnic background, cultural differences and age difference compared to the participants meant that in this piece of work the minority was representing the majority. I think these differences allowed me to probe more deeply and make more observations and led to participants in turn elaborating further, hence these perceived differences were more of an advantage than a hindrance to the research process. Occasionally - for example in the all male Catenians focus group - my differences in age, gender and culture posed difficulties in facilitating the discussion and may have resulted in less probes being used, and hence resulted in poor quality data. However, the presence of the second researcher who had more characteristics similar to the group offset these differences.

However, what perhaps affected the study most was the apparent power dynamics between the participants and the researcher. To facilitate discussions, information on life-prolonging medical technologies and explanations of resuscitation, the do-not-attempt to resuscitate order and advance directives were given to the participants. Hence, the participants viewed me as an authority on the subject or an expert in the area, often posing questions directly at me during the focus group. Since most of the participants suggested that their reason for participating in the project (a question asked as part of the rapport building exercise) was to learn more about the area, I perceived an ethical responsibility to give them as much information as possible on the subject. I, the researcher, provided as much information to the participants, as deemed appropriate, with the view of empowering them. In addition, a short write-up with more details on CPR, survival rates and the legal status of resuscitation were given to participants at the end of the discussion.

The study focused on the sensitive and taboo issues of death and dying and these emotionally-laden discussions could potentially be distressing to both the researcher and the researched. Occasionally I questioned the ethics of asking intimate and personal questions on these issues and often felt that I might have been intruding on personal space. I was aware that personal experiences of participants could affect the discussion and their personal experiences of death, dying and bereavement could be potentially distressing.

The awareness of the emotional labour of the focus group process to both the participants and myself made me more vigilant to adhering to ethical guidelines. At the start of the focus group, we offered the participants as much as information about the topic and also explained that they could withdraw from the study at any point. When a participant broke down, one of the researchers escorted the participants to another room and spoke to them, while the other researcher stayed with the group ensuring that the remaining group members were all right and willing to continue with the discussion. All participants at the debriefing state were given contact details of the researchers, and asked if they wish to discuss any issues further. The option of a follow-up call and a list of organisations that could provide further details about the issues that were discussed were provided.

All participants were offered an opportunity at the debriefing stage of the focus groups to share their experience of participating in the study. Participants suggested that this had been a valuable experience and many called the researcher in subsequent weeks informing us that they had actually spoken to a family member or a doctor and were contemplating signing a living will. Therefore, though not designed as an intervention, the study encouraged people to further think about advance care planning and on occasion conduct advance care planning.

Conducting the focus groups was occasionally emotionally draining for me. I acknowledge that the study was easier to conduct and analyse because the participants seemed healthy and active rather than critically ill or frail. The field notes made during and after the focus group and memos made during the analysis stage, facilitated constant reflection. In addition, the presence of the second researcher and debriefing sessions after the focus group were beneficial for the researcher when exploring sensitive issues such as death and dying.

7.7 Conclusion

The findings from this qualitative study confirmed and strengthened the results of study 2. The qualitative findings suggested explanations and contextualized how older people handle decision making in a realistic, dynamic and complex environment, taking into account the wider social context of resuscitation decision making and advance care planning. The findings also shed light as to why some older people fail to think about advance care planning, because of the negative emotions and denial associated with thinking of their mortality. Therefore a pre-requisite to advance care planning was thinking about and accepting the inevitability of death. Finally, the findings of this study provided further support for older people's preference for discussing their resuscitation preference with their family members.

Chapter 8

Comparing older people and their confidants' views on life prolongation and discussing advance care planning

8.1. Introduction

BMA guidelines recommend that when the patient is incompetent family members should be consulted prior to the resuscitation decision being made. However, the views of family members are intended to reflect the patient's 'best interest' rather than reflect their own values. The role of the family is to aid the clinician to act in the 'best interest of the patient' by informing them about the capacity to benefit and quality of life of the incapacitated patient (BMA, 2001). Confidants have been referred to as surrogates and proxies in the literature. Family members are advised to use the 'substitute judgement standard', where the proxy follows the patient's expressed preferences made before losing the capacity to make decisions. Therefore to act on the patient's best behalf, the older person and their family members should have a discussion about life prolongation, so that family members know about the older person's resuscitation preferences and the values they have used to arrive at this decision.

In the US a proxy decision is legal in some states (Burt, 2003). The role of 'health care proxy' evolved in the United States due to mistrust of physicians and the implications of 'paternalism'. Therefore, close kin make decisions for the patient which they regard as in their best interests. In some States proxies have the authority to discontinue life prolonging treatments. Patients in the US have the authority to choose their own proxies or one is appointed for them. Healthcare proxies have not, however, been effective instruments to facilitate Intensive Care Units decision making for incompetent patients because so few competent patients execute documents appointing such proxies (Burt, 2003). Different rates of proxies have been reported, varying between 5 and 29 % of the populations stating that they have proxies (Committee on Care at the end of life, Institute of Medicine, 1997). Research suggests that patients fail to recognise that they may lose cognitive capacity, and only discuss end-of-life care with their loved ones and medical professionals if the issue is brought up by medical professionals (e.g. Volicer, Cantor, Derse, Edwards, Prudhomme, Gregory, Reagan, Tulskly & Fox, 2002).

Previous studies in this thesis have suggested that older people living in the community would rather discuss resuscitation issues with their family members than their doctors (see Chapters 6 and 7). The results of the focus group study (Chapter 7) suggested that older people saw a clear role for a 'family veto' to the resuscitation decision and wanted their families to act on their behalf. However, some participants suggested that family members know their wishes without explicit discussion. This assumption could make it difficult for family members to act in their relative's best interest if they did not, in fact know what the older person's wishes would be. In the absence of knowing the older person's wishes or the family discussing resuscitation, the danger is that family members may not base their decision on the same values as older people.

Previous research suggests that older people hold the view that the family will determine what is best for them when making end-of-life decisions (e.g. Brock, 1996; Cicirelli, 1997; Emanuel et al., 1992; High, 1988). Historically, physicians and others have routinely relied on family members to serve as proxy decision-makers in long-term facilities where residents commonly have dementia or other illness preventing them from participating in medical decision making (Emmanuel & Emmanuel, 1992). From an evidence-based perspective, most people seem to want their family members to determine what is best for them when they are no longer able to do so (e.g. High, 1988; Sehgal, Galraith & Chesney, 1992; Puchalski, Zhong, Jacobs, 2000). However, the involvement of the family in end-of-life decision making showed variation. For example, Volicer and colleagues (2002) found that 90 % of participants preferred family members as surrogates for end-of-life care decision making. Keith (1983) found that 37 % of elderly parents received advice in making decisions from family members and Pratt, Jones, Hwa-Yong, & Walker (1989) suggests this increased with dependency. Seriously ill and older patients may not make advance care directives because they trust their families to make decisions for them (SUPPORT, 1995).

The systematic study of the healthcare decision making of older adults and their families is in its early stages. Research suggests that older people use a hierarchical preference in choosing proxies: preferring spouses, daughters over sons, sisters over brothers and older children over younger (High, 1988; Roberto, 1999, Wenger & Jerrome, 1999). The importance of geographical proximity to the proxy and mental health of the older person was also associated with having a proxy (Carpiniello, Carta & Rudas, 1989; Guarnaccia et al., 1989; Wenger & Jerrome, 1999). The importance of the confidant relationship for emotional well-being is well documented, being associated with increased life satisfaction, higher morality and lower levels of loneliness and social isolation (see Wenger & Jerrome, 1999). Having a confidant combats depression and psychological distress and may act as social support to older people at the end of life.

Many families do not seriously consider their loved one's preferences for life-sustaining treatment until they are called upon to make a critical decision in the midst of a medical emergency. The stress of these situations can be significantly mitigated when families have the opportunity to discuss and document healthcare plans in advance (Volicer et al., 2002). However, despite BMA guidelines suggesting family involvement in resuscitation decisions for incapacitated patients, there is no uniform standardised process for discussing and documenting specific decisions in advance. Proxies who are confronted with such decisions in the face of an acute change in the patient's clinical condition may feel unprepared, confused or overwhelmed. Anticipating and discussing such decisions in advance can help protect and recognise the interest of vulnerable older people. Many family members who act as proxies are also carers, ranging from occasional visitors to full time caregivers. Continuous care can place a burden of physical, emotional, and financial strain on the carer and as an individual becomes more impaired the burden on the carer increases (Edelmann, 2000). The difficulties are compounded if the carer is also the surrogate decision-maker facing the emotional strain of being part of a DNAR decision for the older person.

The literature in the UK available on proxy decisions making has focused on family members of terminally ill patients and deceased patients who have provided assessments of patient's dying and care in the final stages of life (see McPherson & Addington-Hall, 2003, Seale & Addington-Hall, 1995). Research indicates that family members alter their assessments after bereavement, and retrospective assessment by family members may be valid for service provisions (such as the quality of care at the end of life), but not as the sole assessment of patients' pain, symptoms or anxiety (e.g. Higginson, Priest & McCarthy, 1994; McPherson & Addington-Hall, 2003). If family members inaccurately judge pain, symptoms and anxiety, they are unable to provide an accurate assessment of the quality of life of the dying patient, and are hence ill-equipped to make decisions on life prolongation. There is little available literature from the UK which sheds light on the similarities and differences between older people's and their families' (confidants') views on life prolongation and how they make these decisions. To the best of the author's knowledge there is only one study in the UK comparing older hospitalised patients and their family members' attitudes on resuscitation (Liddle et al., 1994). Liddle and colleagues interviewed and compared the views of 100 older people and 61 of their relatives, 78 % of older people wished for resuscitation, while 70 % of confidants wished for their relative to be resuscitated. The study also asked older people and their relatives for their views about the desirability of resuscitation for different groups: 93 % of older people wished for resuscitation for all older people aged 65 and above as compared to 94 % of confidants; 48 % of older people and 47 % of confidants wanted resuscitation for seriously disabled patients; 24 % of older people and 20 % of relatives thought that CPR was acceptable for demented patients and 18 % of the older people and 16 % of relatives wanted CPR for terminally ill patients. This study suggested that older people and their confidants made resuscitation decisions in a similar manner. Other empirical data from the US has shown that even where proxies have been explicitly chosen by the patient, there is considerable variance between the proxies' beliefs about the patients' preferences and their actual preference (e.g. Uhlmann, Pearlman & Cain, 1988).

Given that the previous studies in this thesis and past research have highlighted the importance of discussions with family members, the aim of the study reported in this chapter was to investigate further the involvement of family members in the resuscitation decision. In this study, the views of older people and their confidant (i.e., a family member whom older people nominate as a person they would like involved in advance care planning) on resuscitation and the factors they both take into account while making resuscitation decisions were assessed. In addition, the values that older people take into account when making choices about resuscitation for themselves were compared with the values that their confidants take into account when making decisions on the choice of life prolongation. Finally, the principles that older people and confidants use when making a decision to discuss life prolongation with each other were explored.

Since the primary aim of the study was to compare the values both parties (older people and their confidants) hold when making resuscitation and advance care decisions, a quantitative approach was considered more appropriate. In addition, the aim was to recruit a diverse sample of older people with different socio-economic backgrounds. Given that the aim was also to recruit a large economically and socially diverse sample, an interview was considered appropriate to elicit the views of these sensitive and potentially distressing issues.

8.2 Research questions and hypotheses

The broad research question examined in this study was the comparison between the older people's and their confidants' attitudes and preferences regarding CPR, including a comparison of the values that predicted these attitudes and preferences (see specific research questions 1-6). Given that older people in the previous studies said they would rather discuss end-life-care with their families than with their doctors, the factors influencing whether or not such discussions take place were also investigated here, and compared between the older person and the confidant groups (research questions 7-8). Finally, the extent of agreement between older people and their confidants in values important when making resuscitation decisions were evaluated (research question 9).

1. Is there a significant difference between older people and their confidants' attitudes towards artificial feeding, ventilation and CPR?
2. What are the predictors of older people's attitudes towards CPR?
3. What are the predictors of confidants' attitudes towards CPR?
4. Is there a significant difference between older people's and their confidant's choice of CPR?
5. What are the predictors of older people's choice of CPR? It was expected that attitudes towards CPR will have an effect on choice of CPR. Therefore, participants who were opposed to CPR would be more likely to reject the use of resuscitation, while those with accepting attitudes towards CPR would have like CPR to be initiated in the case of cardiac arrest.
6. What are the predictors of confidants' choice of CPR?
7. What are the predictors of older people discussing life prolongation with family members? It was expected that participants who did not want their lives prolonged by resuscitation would be more likely to discuss these issues with their confidants.
8. What are the predictors of confidants' discussing life prolongation with family members?
9. To what extent do older people and their confidants agree on important issues regarding life prolongation?

8.3 Method

8.3.1 Participants and recruitment

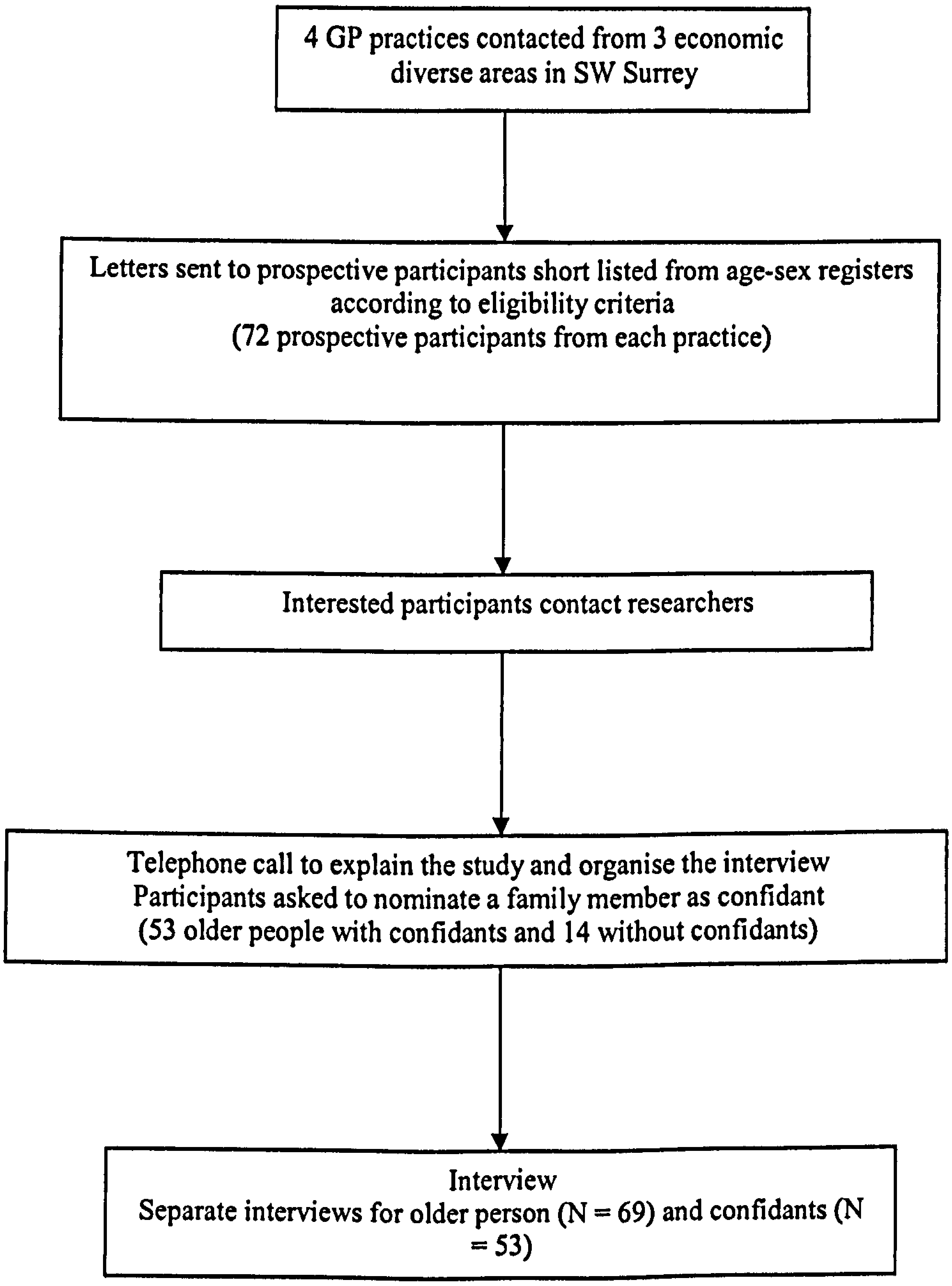
Ethical approval for the study was granted by the South West Surrey Local Research Ethics Committee. Participants were older people in the community recruited from General Practice age-sex registers from economically diverse populations in SW Surrey. The eligibility criteria were: being able to read and comprehend English, currently living in the community, not suffering from dementia, and without cognitive disability or depression. Where possible, a confidant was invited to participate in the study.

The researchers contacted General Practitioners (GPs) from 3 geographical locations (Aldershot, Farnham and Guildford) inviting them to participate in the study. Four GP practices agreed to assist with patient recruitment for the study (two in Guildford and one each in Aldershot and Farnham). Each GP practice identified potential participants based on the eligibility criteria set by the researchers (see Appendix 18 for letter to the GP's).

Participants in the appropriate age categories were sent a letter from their GP inviting them to participate in a study seeking patients' views on health care issues for older people. Those interested were asked to return a postcard with their contact details to be told more about the study (see Appendix 19). Participants who expressed an interest in the study were telephoned by the researcher at a convenient time as indicated in the response post card. The study was described as research investigating older people's views about the challenges of growing old and their views about healthcare. Participants were further told that the research team wished to talk to them about their thoughts and preferences about life prolonging medical technologies and how they wish to be involved in their medical decision making in the later stages of life. Interested participants were told that the researcher was particularly interested in studying older people who are not in hospital, because this was good time for people to think about and make decisions about the kind of care they would like to receive. Participants were told that the aim of the study was to find out how we can help people have good discussions with their doctors and family members about these difficult issues. Participants were then asked to nominate a family member or a confidant they would like involved in these decisions and to participate in the study. Participants who did not want to nominate a confidant or did not have a confidant were still invited to participate in the study. The confidant was normally a family member or friend. There was no age restriction on the confidant. A mutually convenient time was then fixed for the researchers to go to the participant's home to conduct the interview. An information sheet was sent to participants (see Appendix 20 for older person's information sheet and Appendix 21 for confidant's information sheet).

A diagrammatic representation of the recruitment process is presented in Figure 8.1. The recruitment goal was 48 men and 48 women living in the community and (where possible) their confidants (one per participant). Therefore, there would be 24 participants from each of the four GP practices, and 3 in each age-sex category (4 age groups and 2 gender groups – 3 X 4 X 2 = 24). In the first wave of recruitment, Wave 1, a total of 72 letters per GP surgery were sent to prospective participants, 9 for each age-sex category, to allow for a 33 % participation rate. In Aldershot, a further 24 more letters were sent out in Wave 2, and a total of 22 participants were recruited. In Guildford, which comprised of 2 GP surgeries, a total of 26 participants were recruited and in Farnham 21 participants were recruited. Therefore, a total of 69 older people were recruited out of 312 letters sent out to prospective participants. The recruitment rate was 22.11 %.

Figure 8.1: Diagrammatic representation of the recruitment process



8.3.2 Interview schedule

A structured interview schedule was used to elicit information on resuscitation decision making and discussing life prolongation with family members. The themes that emerged from the focus group study were used to design the interview schedule. Before conducting the study, four older people and their confidants were interviewed to pilot the interview schedule and the procedures. The older person's interview schedule (see Appendix 23) and the confidant's interview schedule (see Appendix 24) are described in the next sections.

8.3.2.1 Demographic characteristics

Both older people and their confidants were asked questions regarding their demographic characteristics. The participant's age, gender, marital status, ethnicity, educational level, employment status, religion and living arrangements were recorded. Participants were asked to rate their health status by responding to a 5-point scale, 1 = very good and 5 = very poor. The presence of a long term illness was recorded as 'Yes' and 'No'. Participants were also asked to rate their degree of religiosity on a 5-point scale, ranging from 1 = very religious to 5 = not at all religious.

Confidants were asked additional questions on their relationship with the older person, including whether they lived with them, why they thought they were nominated for the study and whether they were comfortable with the nomination.

8.3.2.2 Older person's interview schedule

Views on life-prolonging measures

The topic was introduced by telling the participants that advances in medical technologies have made it possible to prolong life and these have been used to increase the life span of people. Participants were asked about their views or thoughts on these life-prolonging medical technologies used to increase the life span in the final stages of life. Their attitude towards life prolongation in general was recorded as 1 = 'very opposed' to 3 = 'very acceptable'. Their views for life prolongation for themselves were also recorded as 1 = 'life prolongation', 2 = 'no life prolongation' or 3 = 'did not bring it up'. In addition, participants' attitudes towards three life-prolonging medical technologies (Ventilation, Artificial Feeding and Cardiopulmonary Resuscitation) were explored. Participants were given explanations of these life-prolonging technologies, when needed. Participants were asked to rate the acceptability of each of these procedures on a 5 point scale ranging from 1 = highly opposed to 5 = very acceptable and to give a reason for their score. Due to low frequencies, the response categories were collapsed and recoded into 1 = opposed, 2 = neutral and 3 = accepting. Participants indicated their own choice or preference for resuscitation. This was coded as 1 = would like CPR, 2 = would not want CPR, 3 = did not state preference.

Values important when making decisions of life prolonging medical technologies

Participants were asked what values were important to them when they thought about life prolongation and advance care planning. Participants' responses included: quality of life, family interests or for the sake of the family, burden on family, retaining control and independence, religious conviction, dying with dignity, pain and age. This was initially an open-ended question. However if an item or value was not mentioned, participants were prompted by asking for their views. They were asked if they would take the particular value into account when they thought about their views on resuscitation. Participants who mentioned that they took the value into account were given a score of 1 = yes, and those values that were not considered were given a score of 2 = no.

In addition, autonomy was assessed by asking participants how important it was to be involved in their own medical decisions, by responding to a 5 point scale, ranging from 1 = very important to 5 = not at all important. The frequency of responses at the higher end of the scale was low, therefore these were recoded as 1 = important to 3 = not important. Participants' views on what constitutes an acceptable quality of life was assessed by asking participants whether they considered medical and/or physical function to be important when assessing quality of life. Participants who thought that only physical function was important were given a score of 1, those who held both important were given a score of 2 and those who held only physical function as important were given a score of 3. Participants' attitudes towards death and dying were assessed by asking them whether they thought about death and dying and what their thoughts about these issues were. Participants were prompted by asking them whether their views had changed over the past 10 years. The open-ended responses were recorded as 'fear', 'denial' or 'accepting attitude' or 'others'. Due to fewer responses in the 'fear' and 'denial' categories, the responses were recoded as 1= accepting attitude or 2 = not accepting attitudes towards death and dying.

Discussed life prolongation

Participants were asked questions on their choice of confidant. Participants were asked why they chose the particular person they had nominated. This was an open-ended question, which was later coded into 'only one available' and 'family member'. Participants were asked what factors they took into account when choosing their confidants. Responses to this open-ended question included 'the person knows me best', 'empathy and support', 'previous experience', 'confidentiality' and 'practicality'. Finally, participants were asked whether they would have chosen any one else in the family to discuss life prolongation with. Participants were asked to choose from the following responses: spouse, daughter, son, brother, sister and others.

Participants were asked if they had discussed life prolonging measures with their confidants by indicating 'Yes' or 'No'. Participants who answered 'Yes' were asked questions on their experience of having discussions of life prolongation with their confidants. Participants were asked why they chose to discuss these issues with their confidant or what prompted them to discuss these issues with their family member. This open-ended question included the following response categories: 'age: when one gets older', 'personal experience with illness and death', 'when healthy', 'before going to the hospital', prompted by the doctor' and 'prompted by family member'. Participants were asked how the conversation with the family member started and how it proceeded. This open-ended question included the following response categories: 'I initiated it', 'they initiated the conversation', 'it just happened', 'watching TV' or 'prompted by a book/article etc'. Participants were asked to indicate if the conversation with their family member about life prolongation was 'formal' or 'informal'. These were options presented to participants. Further, participants indicated where the conversation took place, by indicating whether the conversation took place at home, at a funeral, in a cinema or theatre. Participants were given the response categories to answer questions on when ('after an event', 'during an event' or 'some time later'), and why ('because I was troubled', 'trying to make up mind' or 'trying to reassure my companion') by the interviewer. Participants were asked what topics this conversation included by providing the following topics: hospice care, pain control, dying with dignity, funerals, euthanasia, prolonging life. Participants were asked whether there were any follow-up conversations, by asking them whether the conversation was 'just the once' or a 'recurring theme'. Participants were asked about the degree to which the conversation was a discussion rather than just an information-providing exercise. Participants were asked to choose one of the following responses: 'tell them (family member) without regard for their opinion', 'I would respect their views but do what I want', 'I owe it to them to listen to their views', 'I would listen but make up my own mind' or 'half and half'. Participants were asked if they thought that the conversation imposed a burden on the family member or relieved the burden of decision making. Participants were given the option of choosing between 'they felt relieved', 'it imposed a burden on them' or 'no effect either way'. Participants were questioned on the barriers they experienced when discussing these issues with their confidants. This open-ended question was coded according to the following responses: 'my reluctance', 'their reluctance', 'both reluctant', 'no opportunity to do so', 'they live far away' and 'no barrier'. Questions also included problems they encountered. The open-ended question was coded accordingly into the following responses categories: 'finding an opportunity', 'I broke down', 'they broke down', 'death and dying taboo subjects' and 'no problems'. Participants were asked an open-ended question on how they dealt with the problem. Responses were coded as 'finding a specific time', 'tried to reassure them', 'stressed the importance to me' and 'did nothing'. Participants were asked what the outcome of the conversation for them was and what they thought the outcome of the conversation for their confidant was, by choosing from the following response categories: 'felt worse', 'felt better', 'no effect'. Participants were asked what in their view would make it easier to discuss these issues. The responses to this open-ended question were coded as 'if prepare ground', 'if not taboo', 'seize any opportunity', 'over a meal' or 'prompted by TV/ drama programme'. Participants were finally invited to give suggestions to someone who was discussing these issues with a family member. The open-ended question was coded into the following responses 'do not rush them', 'sound them out first', 'come straight to the point' and 'made sure they want to'.

Participants who had not discussed life-prolonging measures with their confidants were asked the following questions. Participants were asked why they chose not to discuss these issues with their confidant. This open-ended question included the following response categories: 'my reluctance', 'their reluctance', 'no opportunity' or 'taboo subject'. Participants were asked on what occasion they would discuss these issues with their confidants. The open-ended response included the following response categories: 'when I go in for an operation', 'when I feel like it', 'if they raise it', 'never- I fear talking about it' or 'never- we both fear talking about it'. Participants were further encouraged to imagine a hypothetical situation in which they would discuss these issues with their confidants. A similar line of questions similar to those presented to those who had discussed life prolongation were initiated. The coding strategy was similar to that used with questions for those who had discussed life prolongation with their confidants.

8.3.2.3 Confidant's interview schedule

Confidants were given a similar interview schedule. In the beginning of the interview they were told that they had been nominated as a 'confidant' or family member who may be consulted to make decisions on behalf of the older person. Some of the questions they would be asked were about their own views on life prolongation and others on their opinion for making these decisions on behalf of their friend or family member. Because the large majority of confidants were in fact relatives, in the description below the term "relative" will be used to describe the older person about whom the confidant was discussing.

Views on life-prolonging measures

This section of the confidant's interview schedule was similar to the older person's interview schedule and was coded in a similar manner. The only difference between the older person and confidant interview schedule was that the confidants were asked to indicate whether they would agree to the use of CPR for their relative, instead of asking about their own preference for the use of CPR. This was coded as 1 = want CPR for their relative , 2 = would not want CPR, 3 = did not state preference.

Values important when making decisions of life prolonging medical technologies

Confidants were asked what values were important to them when they thought about life prolongation and advance care planning, in general. Confidant's responses included: quality of life, family interests or for the sake of the family, burden on family, retaining control and independence, religious conviction, dying with dignity, pain and age. This was initially an open-ended question and coded in the same manner as the older person's responses. Similar to the older person's interview schedule questions were asked about respecting the older person's autonomy on a 5-point scale, ranging from 1 = very important to 5 = not at all important. The frequency of responses at the higher end of the scale was small so these were recoded as 1 = important to 3 = not important. The acceptability of quality of life was assessed by asking participants whether they considered medical and/or physical function to be important when assessing quality of life. It was coded in the same way as the older person's responses. Confidants who thought that only physical function was important were given a score of 1, those who held both important were given a score of 2 and those who held only physical function as important were given a score of 3. Similarly, confidant's attitudes towards death and dying were assessed by asking them whether they thought about death and dying and what their thoughts about these issues were. Confidants were prompted by asking them whether their views had changed over the past 10 years. The open-ended responses were recorded as 'fear', 'denial' or 'accepting attitude' or 'others'. Due to fewer responses in the 'fear' and 'denial' categories, the responses were recoded as 1= accepting attitude or 2 = not accepting attitudes towards death and dying.

Discussed life prolongation

Participants were asked why they thought they had been nominated. This open-ended question was coded as 'I know the person best', 'only one available' or 'practicality'. Confidants were asked whether they were comfortable with the nomination. All participants' responses to this question were positive. Participants were asked if they had discussed life prolonging measures with their confidants by indicating 'Yes' or 'No'.

Confidants who answered 'Yes' were asked questions on their experience of having discussions of life prolongation, identical to those asked to the older person. Similarly, confidants who had not discussed life prolongation with their relatives were asked the same questions that older people who had not discussed these issues were asked.

8.3.2.4 Debriefing

Participants were given an opportunity to ask any questions about the research project and were asked what their feelings and thoughts about this discussion and the research were as a result of the participating in this study. Finally, participants were thanked for their time and participation in the study.

8.3.3 Procedure

All interviews took place in the participants' homes. The interviews were conducted by the author and another researcher from the Centre of Research into Ageing and Gender (CRAG) and two MSc Health Psychology students. The aims of the research were repeated before the interviews and participants were reassured of anonymity and confidentiality. Participants were given the option of withdrawing from the study at any time. Participants were asked to sign a consent form (see Appendix 22) If acceptable to the participants, they were interviewed separately. With permission, the interviews were audiotaped. The interview lasted 40-45 minutes. At the end of the interview, participants were given an opportunity to ask any questions about the research project and were asked for their feelings and thoughts about this discussion and the research in general. Participants were given an information sheet on CPR (see Appendix 17) and a list of organisations that could provide help, information or counselling (see Appendix 3). Participants were also given an option of a follow-up call the following day. Contact information was given to all participants if they wished to contact the researcher. Finally, participants were thanked for their time and participation in the study.

8.4 Data Analysis

8.4.1 Reliability analysis

The responses to the structured questions with predetermined response categories were coded by the interviewers during the interview. The structured questions were subsequently verified by listening to the tapes. The responses to the open-ended questions were noted by the interviewers during the interview. As the interviews progressed these were content analysed and the codes were added to the interview schedule, so that the interviewer could code them during the interview. The unstructured questions were subsequently verified by listening to the tapes. The tapes were listened to by the author and the same researcher from the Centre of Research into Ageing and Gender (CRAG), who assisted with the interviews. The coders were able to code all the responses with these options. Disagreements regarding the responses (both open-ended and structured) were resolved by discussion. The coded data were then entered into SPSS and then subjected to univariate and multivariate statistical analyses.

8.4.2 Data Screening

A total of 7 cases were deleted from the analysis: 4 older people and 3 confidants. These were removed because the interview was incomplete due to the participants breaking down, being confused or too ill to complete the interview.

8.4.3 Statistical Analysis

Statistical analysis was carried out using SPSS 11.0. The results were analysed in the following ways.

- The demographic statistics of older people and confidants were compared by using Chi Squares.
- Independent sample t-tests were used to assess differences between older people's and their confidants' attitudes towards life prolongation: artificial feeding, ventilation and CPR.
- Pearson's product moment correlations were used to ascertain the directions and strengths of the relationship between the variables. Multiple regressions were performed to identify variables that predicted older people's attitudes towards CPR. All variables that were significant at the univariate level were used as predictors at the multivariate level. Similar analyses were used to predict confidant's attitudes towards CPR.
- To assess significant differences between older people and their confidants regarding choice of CPR, a Chi-square was used.
- Logistic regressions were used to examine the predictors of older people's preference (or not) of CPR. Chi-squares were used to assess univariate differences between the groups. Significant predictors at the univariate level were used at the multivariate level. Similar analyses were used to predict confidants' preference (or not) of CPR.
- Logistic regressions were used to examine the predictors of older people discussing life prolongation with their family members. Chi-squares were

used to assess univariate differences between the groups. Significant predictors at the univariate level were used at the multivariate level. Similar analyses were used to predict confidant's discussed life prolongation with their family members.

- The extent of agreement or disagreement between older people and their confidants on important issues regarding life prolongation were calculated manually by the researcher.

8.5 Results

8.5.1 Demographic characteristics

8.5.1.1 Older people

Of the 69 older people included in the final analysis, 36 were women (52.2 %) and 33 men (47.8 %). Sixteen of the participants (23.2 %) were between the age of 65-69, 18 participants (26.1 %) between the age of 70-74, 19 (27.5 %) between the age of 75-79 and 16 (23.2 %) between the age of 80-84. The age-sex distribution of the sample is presented in Table 8.1.

Table 8.1: Age-sex distribution of older people

		Sex Male	Female
Age	65 - 69	4 (25 %)	12 (75 %)
	70 - 74	11 (61.1 %)	7 (38.9 %)
	75 - 79	12 (63.2 %)	7 (36.8 %)
	80 - 84	9 (56.2 %)	7 (47.8 %)

The majority of the participants were white (n = 67, 97.1 %). The majority of participants were married (n = 47, 68.1 %). Equal number of participants had a graduate degree (n = 16, 36.4%) and had no education (n = 16, 36.4 %). Most of the participants had retired (n = 61, 88.4 %) and practiced Christianity (n = 63, 91.3 %). Equal number of participants considered themselves as very religious (n = 17, 24.6 %) or not religious (n = 17, 24.6 %). The majority of the sample lived with others (n = 51, 75 %). Thirty- five participants (50.7 %) had no long term illness. Thirty-eight participants (55.1 %) had not been hospitalised in the past 5 years. The majority of participants described their health as good (n = 54, 78.2

%). Twenty-one participants (30.4 %) were recruited from Farnham, 26 (37.7 %) recruited from Guildford and 22 (31.9 %) recruited from Aldershot.

8.5.1.2 Confidants

The sample included 53 confidants, of which 26 were men (49.1 %) and 27 were women (50.9 %). Twelve confidants (22.6 %) were under the age of 65, 13 each (24.5 %) aged 65-69, 70-74, 75-79 and 2 (2.8 %) between the age of 80-84. The age-sex distribution of the sample of confidants is presented in Table 8.2.

Table 8.2: Age-sex distribution of confidants

		Sex	
		Male	Female
Age	Under 65	3 (33.33 %)	9 (66.67 %)
	65 - 69	7 (53.8 %)	6 (46.2 %)
	70 - 74	8 (61.5 %)	5 (38.5 %)
	75 - 79	6 (46.2 %)	7 (53.8 %)
	80 - 84	2 (100 %)	-

Similar to the sample of older people, the majority of the confidants were white (n = 49, 92.5 %), married (n = 49, 92.5 %), retired (n = 40, 75.5 %) and practiced Christianity (n = 48, 90.6 %). Fourteen participants (34.1 %) had a graduate degree. Equal number of participants considered themselves very religious (n = 13, 24.5 %) and had average levels of religiosity (n = 13, 24.5 %). The majority of the confidants lived with others (n = 51, 96.2 %). The majority of the sample had no long-term illness (n = 37, 69.8 %) and were not hospitalised in the past 5 years (n = 35, 66 %). The majority of the confidants considered their health as good (n = 47, 88.7 %). Seventeen participants (32.1 %) each were recruited from Farnham and Guildford and 19 (35.8 %) recruited from Aldershot.

The demographic characteristics of the older person and the confidants are represented in Table 8.3. Confidants tended to be younger, more likely to be married, and to live with others. On all other demographic variables there are no significant differences between the groups.

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Table 8.3: Demographic characteristics of older people and confidants

		Older person		Confidant		Chi Square
		N = 69	%	N = 53	%	
Age	Under 65			12	22.6	χ = 23.43, df=4, p=.00
	65 - 69	16	23.2	13	24.5	
	70 - 74	18	26.1	13	24.5	
	75 - 79	19	27.5	13	24.5	
	80 - 84	16	23.2	2	3.8	
Gender	Man	33	52.2	26	49.1	χ = .12, df=1, p=.73, NS
	Woman	36	47.8	27	50.9	
Ethnicity	White	67	97.1	49	92.5	χ = .57, df=1, p=.45, NS
	Other	2	2.9	4	7.5	
Marital status	Married	47	68.1	49	92.5	χ = 10.59, df=1, p = .00
	Others	22	31.9	4	7.5	
Education	Degree	16	36.4	16	39	χ = .97, df=2, p = .61, NS
	Second level	12	27.3	14	34.1	
	None	16	36.4	11	26.8	
Employment status	Employed	8	11.6	13	24.5	χ = 3.52, df=1, p = .06, NS
	Retired	61	88.4	40	75.5	
Religion	Christian	63	91.3	48	90.6	χ = .00, df=1, p = 1, NS
	None	6	8.7	5	9.4	
Degree of religiously	Very religious	17	24.6	13	24.5	χ = .16, df=4, p = .99, NS
	Religious	11	15.9	8	15.1	
	Average	16	23.2	13	24.5	
	Not religious	8	11.6	5	9.4	
	Not at All	17	24.6	13	24.5	
Who does the person live with	Alone	17	24.6	2	3.8	χ = 13.98, df=3, p = .02
	Spouse	42	60.9	46	86.8	
	Family	9	12.9	5	9.5	
Long Term Illness	Yes	34	49.3	16	30.2	χ = 4.52, df=1, NS
	No	35	50.7	37	69.8	
Hospitalised in the last 5 years	Yes	31	44.9	18	34.0	χ = 1.08, df=1, p = .30, NS
	No	38	55.1	35	66.0	
Self reported level of health	Good	54	78.3	47	88.7	χ = 2.28, df=1, p = .13, NS
	Others	15	21.7	6	11.3	
Recruitment	Farnham	21	30.4	17	32.1	χ = .43, df=2, p = .80, NS
	Guildford	26	37.7	17	32.1	
	Aldershot	22	31.9	19	35.8	

8.5.2 Attitudes towards Life prolongation

Participants were asked to indicate their views towards artificial feeding, ventilation and CPR. In general, the sample had more favourable attitudes towards CPR and ventilation than artificial feeding. Independent sample t-tests were conducted to check if there were significant difference between views of older people and their confidants on artificial feeding, ventilation and CPR (see Table 8.4).

Table 8.4: Mean and Standard Deviations for views of older people and their confidants on life prolongation

	Older person (N =69) Mean (SD)	Confidant (N = 53) Mean (SD)	Significance Test
ATTVEN	2.07 (.85)	2.30 (.80)	t = .1.52, df =120, p = .13
ATTAF	1.91 (.84)	2.11 (.82)	t = -1.32, df =120, p = .19
ATTCPR	2.29 (.78)	2.60 (.69)	t = -2.30, df =120, p = .02

Note: ATTVEN- attitude towards ventilation, ATTAF- attitude towards artificial feeding, ATTCPR- attitude towards CPR. 1= opposed 3 = accepting.

The results indicate that there are no significant differences between the views on artificial feeding and ventilation between older people and their confidants. However, there were significant difference between older people and their confidants' views on CPR, with confidants more likely to have more accepting views on CPR.

8.5.3 Correlates of attitudes towards CPR for older people

Demographic variables (age and sex) and values important when making decisions about life prolongation were used to predict older people's attitudes towards CPR. The inter-correlations between attitudes towards CPR, age, sex and values important when making decisions on life prolongation are shown in Table 8.5.

The results suggest that men were more likely to have favourable attitudes towards CPR. In addition, older people were more likely to accept resuscitation for the sake of the family and more likely to oppose resuscitation in advanced age.

Table 8.5: Correlations between older people's attitudes towards CPR, age, sex and values important when making decisions about life prolongation, and correlations among values (n = 69)

	Mean (SD)	Age	Sex	Value. qol	Value. family	Value. burden	Value. indepen	Value. religious	Value. dwd	Value. pain	Value. age	Value. autonom	Acc. qol	Attitude. death
Att.CPR	2.29 (.79)	.05	-.45**	-.03	-.37**	.22	.00	.19	.12	.19	.44**	.07	.04	-.04
Age	3.51 (1.09)		-19	.04	-.01	.14	-.02	.21	-.01	.07	.00	-.11	.17	-.11
Sex	1.52 (.50)			-.01	-.05	-.01	.04	.02	-.08	-.21	-.29*	.24*	-.03	.01
Value. qol	1.09 (.28)				-.07	.10	.05	.01	.06	.14	.21	-.17	.03	.13
Value. family	1.61 (.49)					.34**	.36**	.34**	.09	.24	.15	.04	.12	.04
Value. burden	1.51 (.50)						.37**	.47**	.11	.31**	.38**	.02	.05	-.19
Value. indepen	1.59 (.49)							.24*	.14	.17	.07	-.04	.01	.04
Value. religious	1.83 (.38)								.18	.19	.01	.03	.14	-.19
Value. dwd	1.75 (.43)									.27*	.19	.13	.08	.02
Value. pain	1.83 (.38)										.34**	.01	-.18	.09
Value. age	1.68 (.47)											.01	.00	.10
Value. autonom	1.68 (.65)												.10	-.04
Acc. qol	2.52 (.58)													.06
Attitude. death	1.64 (.48)													

Note: ATT.CPR - attitude towards CPR (1=opposed, 3= accepting), Value.qol – value of quality of life, value .indepen- value of independence, value.dwd- value for dying with dignity, value,autonom- value for autonomy, (1 = Yes 2= No). Acc.qol- acceptability of QOL (1 = physical function important, 2 = both were important and 3 = mental function important), Attitude. death – Attitude towards death and dying (1= accepting attitude, 2 = not accepting attitudes towards death and dying

8.5.4 Predicting attitudes towards CPR among older people

A standard multiple regression analysis (independent variables were entered into the equation at once) was used to predict attitudes towards CPR (see Table. 8.6). Variables that were significantly correlated with attitudes towards CPR at the univariate level were used as independent variables, namely gender, value for family and value for age. Only significant correlates with attitudes towards CPR were included in the equation to restrict the number of predictors. Tabachnick & Fidel (1996) suggested that correlations between predictive variables should be less than .70.to guard against multicollinearity. Only value for age negatively correlating with gender (r = -.19*). Hence all the variables were included in the regression. The 3 variables were able to explain nearly 34 % of the variance in attitudes towards CPR, adjusted $R^2 = 0.36$, ($F(3, 68) = 12.69$, $p < 0.01$).

Gender, value for family and value for age were all significant predictors of attitudes towards CPR for older people. More specifically, men were more likely to have more favourable attitudes towards CPR. Participants who mentioned family and age as values to consider in end-of-life decision making were less likely to have accepting attitudes to CPR

Table 8.6: Multiple Regression predicting older people's attitudes towards CPR.

	B	Std. Error	Beta	t	sig
Gender	-.52	.16	-.33	-3.22	.00
Value. family	.50	.16	.31	3.15	.00
Value. Age	.46	.17	.27	2.62	.01

8.5.5 Correlates of attitudes towards CPR for confidants

Demographic variables and values important when making decisions about life prolongation were used to predict confidant's attitudes towards CPR. The inter-correlations between attitudes towards CPR, age, sex and values important when making decisions on life prolongation are shown in Table 8.7. The results indicate that confidants who were opposed to CPR were more likely to take into account age and the older person's autonomy.

Table 8.7: Correlates between sex, age, values important when making decisions about life prolongation and ATTCPR (n = 53)

	Mean (SD)	Age	Sex	Value. qol	Value. fly	Value. burden	Value. ind	Value. rel	Value. dwd	Value. pain	Value. age	Value. aut	ACC QOL	att death
ATTCPR	2.60 (.69)	.01	-.14	-.22	.07	-.07	.10	-.04	-.06	-.20	.32*	-.31*	.11	.17
age	2.62 (1.19)		-21	.14	-.04	-.08	.05	.17	.01	.00	-.09	-.22	.27	-.02
sex	1.62 (.49)			.02	.29*	.11	.05	-.05	-.20	.01	-.11	.33*	-.13	-.13
qol	1.06 (.23)				.20	.10	.11	.13	.02	.08	-.12	.07	.11	-.07
fly	1.58 (.50)					.03	.20	.28*	.13	-.14	.18	-.05	.13	.03
burden	1.47 (.50)						.09	.06	.35*	-.08	.08	-.02	-.07	.17
ind	1.43 (.50)							.02	.13	-.24	.05	-.16	-.27	-.06
rel	1.77 (.42)								.23	.13	.15	-.15	-.08	.24
dwd	1.62 (.49)									-.25	.00	-.07	-.19	.27
pain	1.91 (.29)										-.14	.15	.01	-.08
age	1.85 (.36)											-.24	.15	.19
aut	1.77 (.78)												-.38**	-.15
ACC QOL	2.40 (.60)													.17
att death	1.47 (.50)													

Note: ATT.CPR - attitude towards CPR (1=opposed, 3= accepting), Value.qol – value of quality of life, value .indepen- value of independence, value.dwd- value for dying with dignity, value,autonom- value for autonomy, (1 = Yes 2= No). Acc.qol- acceptability of QOL (1 = physical function important, 2 = both were important and 3 = mental function important), Attitude. death – Attitude towards death and dying (1= accepting attitude, 2 = not accepting attitudes towards death and dying).

8.5.6 Predicting attitudes towards CPR among confidants

A standard multiple regression analysis (independent variables were entered into the equation at once) was used to predict attitudes towards CPR (see Table. 8.8). Variables that were significantly correlated with attitudes towards CPR at the univariate level were used as independent variables, namely value for age and value for the older person's autonomy. This approach was used to restrict the number of predictors. The two dependent variables were not correlated and hence were included in the regression. The two variables were able to explain only 13 % of the variance in confidants' attitudes towards CPR, adjusted $R^2 = 0.16$, ($F(2,52) = 4.14$, $p < 0.01$).

The results indicate that only the value for the older person's autonomy was a significant predictor of attitudes towards CPR for confidants. Participants were likely to have opposing attitudes towards CPR if they respected the older person's autonomy.

Table 8.8: Multiple regression: predicting confidants' attitudes towards CPR

	B	Std. Error	Beta	t	sig
Value. Age	.42	.25	.22	1.64	.10
Value. Autonomy	-.26	.11	-.29	-2.19	.03

8.5.7 Choice of CPR

Twenty-six (37.68 %) older people wanted their lives prolonged by CPR, while 29 (42.03 %) did not want life prolongation. Fourteen (20.29 %) older people did not indicate their preference for life prolongation and these were not included in the analysis. Eighteen confidants (33.96 %) wanted their relatives lives prolonged by CPR, while 22 (41.42 %) did not want any life prolongation conducted on their relative. Thirteen (24.53 %) did not indicate their preference for life prolongation for their relative and were not included in the analysis. A Chi-square was conducted to assess significant difference between older people and their confidants' choice of life prolongation. The results suggest that there were no significant differences between the groups ($\chi = .05$, df =1, p=.83).

8.5.8 Predicting older people's choice of CPR

A multivariate logistic regression was used to identify variables that distinguished between older people who wanted CPR and those who did not. Variables that distinguished between the two groups at the univariate level were included in the multivariate analysis. Chi-squares were conducted on all demographic variables and values important when making decision on life prolongation. Only statistically significant values are shown in Table 8.9.

Table 8.9: Significant comparisons between older people who wanted CPR and those who did not want CPR

Variable	Life prolong (n = 26)	No life prolong (n = 29)	Chi Sq statistic	df	p-value
Value. Family			4.49	1	.03
Yes	7	16			
No	19	13			
Value. Age			5.56	1	.02
Yes	4	13			
No	22	16			
Attitude towards CPR			16.62	2	.00
Not accepting	5	21			
Accepting	21	8			
Gender			5.14	1	.02
Male	16	9			
Female	10	20			

A Logistic Regression was used to predict choice of CPR. A test of the full model against a constant-only model was statistically significant. Using this set of predictor variables, 74.5 % of the cases were correctly classified. This finding indicates that the ability of the model to distinguish between the groups is reasonably good. Table 8.10, shows the regression coefficient, standard error, Wald statistic and odds ratio for each predictor variable.

Table 8.10: Logistic regression predicting older people's choice of CPR

Variable	B	SE	Wald	p-value	OR	95 % C.I.for EXP(B)
sex	.34	.74	.22	.64	1.41	.13 – 3.21
Attitude towards CPR	-1.40	.58	5.74	.02	.25	.14 – 2.12
Value. family	-.67	.70	.92	.34	.51	.10 – 2.86
Value. Age	-.52	.80	.42	.51	.59	.19 - .75

Model chi-square 18.38, df = 4, p = .00

According to the Wald criterion, only attitude towards CPR is statistically significant. The OR for attitudes towards CPR indicates that those who held more accepting attitudes towards CPR were more likely to want their lives prolonged by CPR.

8.5.9 Predicting confidants' choice of CPR

Chi-squares were conducted on all demographic variables and values important when making decision on life prolongation. As shown in Table 8.11, only hospitalisation in the past 5 years was a significant predictor at the univariate level. Therefore, multivariate analysis was not required.

Table 8.11: Significant comparisons between confidants who wanted CPR and those who did not want CPR

Variable	Life prolong (n = 21)	No life prolong (n = 23)	Chi Sq statistic	df	p-value
Hospitalised in the past 5 years			4.05	1	.04
Yes	4	11			
No	17	12			

8.5.10 Discussing life prolongation with family members

The majority of older people (n = 50, 72.5 %) has not discussed life prolongation with their confidants, as compared to 19 older people (27.5 %) who had discussed these issues with their confidants. Similarly, confidants suggested that they had not discussed life prolongation with their older family members (n = 32, 60.4 %), as compared to 21 (39.6 %) confidants who thought they had discussed life prolongation with their relatives. A small proportion of confidants (n = 8, 15.09 %) thought that they had discussed life prolongation with their older person, while the older person thought they had not discussed these issues, indicating that there can be a misunderstanding as to whether these issues have been discussed.

8.5.11 Predicting whether older people had discussed life prolongation with family members

A multivariate logistic regression was used to identify variables that distinguish between older people who had discussed life prolongation with their family members and those who had not. Variables that distinguished between the two groups at the univariate level were included in the multivariate analysis. Chi-squares were conducted on all demographic variables and values important when making decision on life prolongation. Only statistically significant values are shown in Table 8.12.

Table 8.12: Significant differences between older people who had discussed life prolongation with their family members and those who had not.

Variable	Discussed (n= 19)	Not discussed (n=50)	Chi Sq statistic	df	p-value
Value. QOL			5.04	1	.02
Yes	15	48			
No	4	2			
Attitude towards death and dying			7.58	1	.01
Not accepting (fear and denial)	2	21			
Accepting	17	24			
Choice for LP			3.51	1	.06
Life prolongation	4	22			
No life prolongation	11	18			

At the univariate level, value for quality of life, and attitude towards death and dying were statistically significant and choice for life prolongation was marginally significant and was included in the regression. A Logistic Regression was used to predict older people discussing life prolongation with their family members. A test of the full model against a constant-only model was statistically significant. Using this set of predictor variables, 76.4 % of the cases were correctly classified. This finding indicates that the ability of the model to distinguish between the groups is reasonably good. Table 8.13, shows the regression coefficient, standard error, Wald statistic and odds ratio for each predictor variable.

Table 8.13: Logistic regression predicting older people discussing life prolongation with family members

Variable	B	SE	Wald	p-value	OR	95 % C.I.for EXP(B)
Value. QOL	-1.35	1.11	1.48	.22	.26	.03 – 2.28
Attitudes towards death and dying	-1.78	.84	4.49	.03	.17	.03 - .87
Choice of life prolongation	-1.07	.71	2.27	.13	.34	.08 – 1.38

Model chi-square 11.76, df = 3, p = .01

According to the Wald criterion, only attitudes towards death and dying was statistically significant. The OR for attitudes towards death and dying indicates that those who held more accepting attitudes towards death and dying were more likely to discuss life prolongation with their family members. Participants who had accepting attitudes towards death and dying were .17 times more likely to have discussed life prolongation with family members than participants than those who had less accepting attitudes towards death and dying. . Therefore, participants who had positive attitudes towards death and dying were more likely to discuss life prolongation with their families than their counterparts.

8.5.12 Predicting confidants who had discussed life prolongation with family members

A multivariate logistic regression was used to identify variables that distinguish between confidants who had discussed life prolongation with their family members and those who had not. Variables that distinguished between the two groups at the univariate level were included in the multivariate analysis. Chi-squares were conducted on all demographic variables and values important when making decisions on life prolongation. Only statistically significant values are shown in Table 8.14.

Table 8.14: Significant differences between confidants who had discussed life prolongation with their family members and those who had not.

Variable	Discussed (n = 21)	Not discussed (n = 32)	Chi Sq statistic	df	p-value
Value. QOL			4.84	1	.03
Yes	18	32			
No	3				
Value. Family			7.23	1	.01
Yes	4	18			
No	17	14			
Value. Pain			3.76	1	.05
Yes	4	1			
No	17	31			
Attitude towards death and dying			15.93	1	.00
Not accepting (fear & denial)	4	24			
Accepting	17	8			

A Logistic Regression was used to predict confidants discussing life prolongation with their family members. A test of the full model against a constant-only model was statistically significant. Using this set of predictor variables, 86.8 % of the cases were correctly classified. This finding indicates that the ability of the model to distinguish between the groups is reasonably good. Table 8.15, shows the regression coefficient, standard error, Wald statistic and odds ratio for each predictor variable.

Table 8.15: Logistic regression predicting confidants discussing life prolongation with family members

Variable	B	SE	Wald	p-value	OR	95 % C.I.for EXP(B)
Value. qol	- 11.15	50.97	.05	.83	.00	.00 - .69
Value.family	- 2.28	.97	5.47	.02	.10	.01 - .69
Value.pain	3.77	1.94	3.76	.05	43.19	.96 – 19.13
Att.death	- 4.32	1.26	11.82	.00	.01	.00 - .16

Model chi-square 38.78, df = 4, p = .00

According to the Wald criterion, value for family, attitude towards death and dying were statistically significant and value for pain was marginally significant. The OR for attitudes towards death and dying indicates that confidants who held more accepting attitudes towards death and dying were more likely to discuss life prolongation with their family members. In addition, confidants who took into account values for the family were more likely to discuss life prolongation with their family members. The OR for value for pain indicates that confidants who held pain as an important criteria were 43.19 times more likely to discuss life prolongation with their family members.

8.5.13 Extent of agreement and disagreement between older people and their matched confidant's on important issues of life prolongation

The extent of agreement and disagreement between older people and their matched confidants on values important when making decisions regarding CPR and decisions whether to discuss these issues with family members were directly compared. This was done manually by the researcher, by comparing 52 pairs of older people and their confidants. The values compared were: quality of life, for the family, burden, independence, religion, dying with dignity, autonomy, acceptability of quality of life and attitudes towards death and dying. If both the older person and the confidant gave an answer of 'yes' or if both answered 'no' they were considered to agree. However, if they answered differently (for example, the older person said 'yes' while the confidant answered 'no' or vice versa) they were considered to disagree. The degree of agreement and disagreement between the older person and confidants on these values are presented in Table 8.16. In addition, the degree of agreement and disagreement between pairs of older people and confidants on attitudes towards CPR, choice of CPR and whether they had discussed life prolongation are shown in Table 8.17.

The results suggest that there was a wide range of agreement between older people and their matched confidants with regard to importance of values when making life prolongation decision, ranging from 46 (88.46 %) to 25 (40 %). More importantly, 75 % of older people and their confidants agreed that a discussion regarding life prolongation had taken place between them, 51.62 % agreed on the choice of CPR and only 36.54 % agreed on their attitude towards CPR.

Table 8.16: Extent of agreement and disagreement between pairs of older people and their confidants on important issues of life prolongation

Variable	agreement (%)	disagreement (%)
value.qol	46 (88.46)	6 (11.54)
value.religion	39 (75)	13 (25)
value.pain	35 (67.31)	17 (32.69)
value.age	35 (67.31)	17 (32.69)
value.dwd	34 (65.38)	18 (34.62)
value.burden	33 (63.46)	19 (36.54)
attitudes towards dying	33 (63.46)	19 (36.54)
acc.qol	32 (61.54)	20 (68.46)
value.autonomy	29 (55.77)	23 (44.23)
value.independence	28 (53.85)	24 (46.15)
value.fly	25 (40.08)	27 (51.92)

Table 8.17: Extent of agreement and disagreement between pairs of older people and their confidants on attitude towards CPR, choice of CPR and discussed life prolongation

Variable	agreement (%)	disagreement (%)
Discussed life prolongation	39 (75)	13 (25)
Choice for CPR for older person	31 (51.62)	21 (40.88)
Attitude towards CPR	19 (36.54)	33 (63.46)

8.6 Discussion

BMA guidelines suggest that family members should be involved in the resuscitation decision and should act in the best interest of the patient. Previous studies have shown that even though older adults give serious thought to who would act as their surrogate decision maker and would prefer their families in this role, they do not necessarily discuss their wishes with their families or put their wishes in writing (e.g. Damato et al., 1993). Older people assume that family members intuitively know their values and hence are best equipped to make these decisions. This study was particularly important as it compared the views of older people and their confidants on resuscitation and advance care planning, taking into account the factors involved in the decision making process.

Views on life prolongation

The results suggest that older people and their confidants had more opposed views towards ventilation and artificial feeding, which were perceived as invasive and long-term, rather than CPR. It is possible that older people considered that CPR was more likely to be successful, while artificial feeding and ventilation involved gadgets and machines being attached to the body of a dying person. Eating and breathing are considered essential to human life, the perception being that if one is unable to eat or breathe without assistance, then one would have a low quality of life. This could explain why there was more opposition towards artificial feeding and ventilation. Both older people and their confidants had moderately accepting attitudes towards CPR. The sample consisted of older people (and their confidants) who were reasonably healthy, living in the community and not currently hospitalised. Hence it could be assumed that they had a fairly good quality of life and therefore had more accepting attitudes towards resuscitation.

More importantly, older people were more likely to have negative attitudes towards resuscitation than their confidants. Possible explanations for confidants being more accepting of CPR than their relative may reflect the likelihood that making a decision of life and death for someone else, as would be the case for a confidant, is particularly stressful. Opposing resuscitation for a dying family member could be viewed as conferring a death sentence upon them. In addition, imagining the death of a loved one is particularly distressing for family members and hence they may be more likely to accept the inevitability of death if they knew that everything possible had been done to try to save their relative.

Older people and their confidants used different values when assessing their attitudes towards CPR. Older men were more likely than older women to have positive attitudes towards resuscitation. Previous studies and past research (see Chapter 6) confirm this finding. In addition, older people with more accepting views towards CPR held the value of having resuscitation for the sake of the family and value for age are important. Opposing resuscitation or signing a DNAR order implies that CPR will not be attempted and death is inevitable. This decision influences not only the individual but also the family, who bear the burden – emotional, psychological and economic - of the bereavement. Hence it is not surprising that older people consider the wishes of their family when assessing their views of resuscitation. The 'value for the family' factor is similar to the subjective norms construct of the theory of planned behaviour (TPB). The importance of subjective norms in decision making regarding life prolongation and advance care planning was addressed and discussed in Chapter 6. The value of age was also viewed as an important consideration in relation to attitudes towards CPR. A plausible reason for this was that advanced age is perceived to result in low quality of life.

In contrast to older people, confidant's views on resuscitation were influenced by the older people's autonomy. This implies that confidant's views on resuscitation were directly influenced by what the older person wanted in terms of resuscitation and highlights the importance of communication between family members about life prolongation. However, the variance accounted for by this factors was low (13 %), suggesting that perhaps confidants also took other factors into account when assessing their attitude towards CPR for their relative. The aim of this study was to assess whether confidant's attitudes towards CPR are influenced by the same factors as those influencing the views of older people towards resuscitation. The findings of this study suggest that confidants' attitudes towards CPR are influenced by different factors and more research is needed to identify the factors that influence confidant's attitudes towards resuscitation.

Choice of CPR

Older people's choice of whether to undergo CPR was influenced by their attitude towards the procedure. Those with more favourable attitudes towards resuscitation were more likely to want resuscitation, while those with opposing attitudes were more likely to decline CPR. In terms of social cognitive models, such as the TPB, attitude has an influence on behaviour choice. At the univariate level, value for age, value for family and gender also predicted a decision in favour of CPR. However, since all these variables predicted attitudes towards resuscitation, only attitude towards resuscitation predicted choice of resuscitation.

The decision of a confidant in favour of CPR for their relative was influenced by whether the confidant had been hospitalised in the past 5 years. In other words, confidants who had been hospitalised were less likely to be in favour of CPR for their relative. Contrary to expectation, confidant's attitudes towards CPR did not predict whether they preferred CPR for their relative. This result is promising as it suggests that confidant's attitudes towards CPR did not influence their choice of CPR for their family members, which therefore was influenced by other factors, perhaps one more particular to their relative. The result suggesting that confidants who were hospitalised in the past 5 years were more likely to oppose CPR is difficult to interpret. Apparently, their own experience of illness and hospitalisation has an influence on them not wanting resuscitation for their relative. It would be interesting to further explore this finding in a qualitative approach.

Discussing life prolongation with family members

The majority of older people (72.5 %) and their confidants (60.4 %) had not discussed life prolongation with each other. These results are comparable to similar studies in the US (e.g. Seckler, Meier, Mulvihill & Paris, 1991; Broadwell, Boisaubin, Dunn & Engelhardt. 1993). In Seckler and colleagues (1991) study of 70 older adults recruited from a geriatric outpatient clinic, only 16 % reported having a conversation with their proxy. In the present study, 15.09 % of older people and their confidants disagreed on whether they had discussed these issues with each other.

The results of this study indicate that a small proportion of confidants thought that they had discussed life prolongation with their older person, while the older person thought that no such discussion had taken place, indicating that there can be a misunderstanding as to whether these issues have been discussed. Other studies have shown similar trends. For example, Cilirelli (2002) reported that in his study of family caregiving and decision making, 42 % of the 62 older patients and 20 % of their 62 adult children indicated never having discussed the patients' wishes for health care. A potential reason for these misunderstandings could be due to the informal or implicit nature of the conversation. Older people informally or indirectly seek the advice of their family with regard to health problems and treatment options (Hickey, 1988, Stein, 1989). It is hence important that discussions about life-prolongation are made explicit so that the confidant is fully aware that the older person has communicated their views regarding life prolongation.

In addition, the values held by the confidants on pain and the family could be used to predict the likelihood of life-prolongation discussions taking place. If relatives are in pain, confidants view this as a low quality of life and therefore are more likely to discuss life prolongation with their relative. It is however unknown whether pain motivates older people to discuss these issues with their relatives or whether the sight of their relative in pain motivates family members to initiate the discussions. Additionally, confidants take into consideration family views (both of the ageing relative and of other family members) when making the decision to discuss life prolongation.

Agreement between older people and their family members on life prolongation issues

The results comparing agreement between older people and their confidants indicated that there was only 75 % agreement between their views as to whether a discussion regarding life prolongation had taken place. This finding suggests that there is sometimes (here in 25% of cases) a misunderstanding as to whether the conversation had occurred. If there is miscommunication, or failure to appreciate that such a communication had taken place, the confidant is unable to act in the interest of their relative. Older people may think that they have communicated their intention with regard to CPR, while confidants may be unaware that the conversation has taken place. A plausible reason for this is that such conversations often occur at home, possibly in an informal setting while watching media coverage related to death and dying or mentioned in passing during a conversation about someone else. These conversations are often general rather that specific and therefore there is potential for miscommunication.

More importantly, there was just over 50 % agreement between pairs of older people and their confidants in the choice of CPR for the older person. In an issue as sensitive as this, close to 100 % agreement would be preferable. Other studies comparing older people and their confidants' views of resuscitation for specific hypothetical scenarios have found similar results of poor to fair concordance (Matheis-Kraft & Roberto, 1997; Seckler et al., 1991; Uhlmann et al., 1988). The lack of agreement between older people and their confidants may be due to the different factors that are important to each party when framing resuscitation and advance care decisions.

Implication for practice

The findings of this study suggest that discussions of life prolongation within the family setting are not routinely conducted. If family members are to be involved in resuscitation decision making and their views are to reflect the interests of their relative, it is imperative that these discussions take place. The findings of this study can be used to understand the factors that enhance discussions on these sensitive issues and to design interventions that will encourage communication on life prolongation within the family setting. Older people and their confidants were more likely to discuss life prolongation with each other if they had accepting attitudes towards death and dying. In contrast, those who were in denial about their death or feared death were less likely to accept the inevitability of their mortality and procrastinated discussing life prolongation. As suggested in chapter 2, contemporary western society denies the inevitability of death and there is a taboo on discussing issues of death and dying. These societal values are hard to break. Life prolongation involves thinking about and discussing death and as such is difficult for all parties involved.

Suhl, Simons, Reddy & Garrick (1994) reported that the more discussions the older adult and their family members had regarding older peoples' feelings about receiving life support, the more accurately the surrogate understood the wishes of their relative regarding life sustaining treatment. Thus, if family members are to be involved in resuscitation decisions, they need to discuss these issues with their relative.. Perhaps the legalisation of the healthcare proxy, as in the US, will make the process of involving family members in the decision making more formal and will raise awareness of the importance of communicating with family members about wishes regarding resuscitation.

Our experience of conducting the interviews suggested that the involvement of a third, neutral party could make such conversations less distressing. More importantly, these interviews helped older people and their confidants evaluate their own beliefs and values about death and dying, thereby making it easier for them to discuss such issues with their loved ones. Although not intended, this study acted as an intervention. By discussing life prolongation with the interviewers, older people and their confidants realised that these discussion were not as stressful as they had anticipated. At the end of the interviews participants commented on the value of the study, often phoned the researchers asking for advice, and informed the researchers that they had initiated these conversations with the member of the family who had participated in the research and other family members. However, in a few cases, the interview proved distressing and had to be terminated, indicating that this is a sensitive topic and can only be raised with people ready and willing to discuss it. In other respects, some older people and their confidants who had not discussed these issues with each other found it hard to hypothesise having these discussions.

This study employed structured interviews to assess the values that older people and their confidants used to make decisions about resuscitation and advance care planning, and examined discussing life prolongation with each other. Previous studies in the thesis only assessed older people's views on resuscitation and advance care planning, while the views on confidants were not evaluated. Some questions were open-ended, allowing for unexpected and novel ideas to emerge. Moreover, the coding guide was updated as new codes emerged. However, the interview data were converted to quantitative data to allow reliable comparisons between older people and their family members. Despite the success of the study in shedding light on the different ways in which older people and their confidants make resuscitation and advance care decisions, more research is needed on how confidants anticipate making decisions on behalf of their relatives, either without having discussions about life prolongation or in the event of them having had prior discussion with family members.

The study had various limitations, particularly with regard to the sample. The low recruitment rate suggests that many people may view the subject of death and dying as distressing and our findings and interpretation are limited by our ability to only evaluate the attitudes of those who were willing to participate in the study. It is interesting to note that recruitment was harder in low socio-economic areas, such as Aldershot, where the required target was reached after 2 recruitment waves.

The sample recruited in this study was fairly representative in terms of age, gender and education status in comparison to the previous studies (see Chapter 5, 6, 7). More participants were likely to have reported the presence of a long-term illness; however a large proportion of them reported their health as fairly good. The results of this study are hence applicable to an older population willing to talk about death and dying who are of good health. It is possible that views would be different for older people closer to death and/or living with a terminal illness, and for the very old. More research on such groups, including ethnic minorities, is needed and their views may be different.

Finally, in this study the older person had more time to consider some of the issues raised in the interview, since the researchers had spoken to them personally during recruitment. In the case of the confidant, who were nominated by the older person, was aware of the area being discussed and the broad thrust of the interviews but they did not have the opportunity to contemplate these issues in advance. Some of their replies indicated that they had not thought deeply about end of life decisions before the interview. Their initial responses may not fully reflect the nuances of their views which they arrived at after considering the issue more deeply as a result of the interview.

8.7 Conclusions

Proxy decision making is intended to ensure continued autonomous choice for the non-autonomous patient. Decisions made by the confidant should be consistent with the choice that the patient would have made. This study suggests that this may not be the case because confidants use different values when making decisions regarding resuscitation and advance care planning. Moreover, confidants do not necessarily know their relative's wishes.

Chapter 9: General Discussion

9.1 Overview

This chapter reviews the findings presented in the previous chapters and synthesises them to provide answers to the general research questions posed at the beginning on the thesis. The general aim of the thesis was to understand community dwelling older people's perspectives towards resuscitation orders and advance care planning. More specifically, the thesis aimed to develop and test a psychological model of the process of resuscitation decision making and advance care planning for older people living in the community. This research also sought to gain insight into which means of advance care planning older people preferred and why. Using a social cognitive theoretical approach (specifically, the Theory of Planned Behaviour; TPB), this thesis posed some novel questions regarding older people's understanding of advance care planning and attempted to answer them using both qualitative and quantitative methodologies. Both methods were used because they each have different strengths and weaknesses and, together, were expected to provide a more complete understanding of older people's views on advance care planning. In this thesis, advance care planning was defined as signing living wills, and/or discussing life prolongation with the doctors and/or family members.

In the proceeding sections of this chapter, in addition to summarising the findings presented in the previous chapters, the appropriateness of the TPB as a theoretical framework will be evaluated. The advantages and disadvantages of using both qualitative and quantitative methods will be discussed. The limitations of the research and directions for future work will be reviewed. Finally, implications for practice and policy will be highlighted, and a personal reflection is offered.

9.2 Integrative Summary

Chapter 1 provided a synopsis of the contents of the thesis. The purpose of Chapter 2 was to understand the legal, medical and historical background of resuscitation decision making in the UK. The development of medical technology enables individuals to prolong the dying process and sometimes defer death without consideration for an individual's dignity and quality of life. The main conclusions of this chapter were that the BMA guidelines, intended to safeguard the patient's rights of autonomy and self-determination are mere tokenism, since the guidelines imply that the doctor has superior knowledge about CPR and these decisions are normally made in a hospital setting, closer to the time of death, where the patient may not be competent to participate in the decision making process. Besides the legal and medical factors, various social and historical factors affect the resuscitation decision. With the advent of life-prolonging and life-sustaining technologies, even "death" itself has become a difficult concept to define. In addition, there are various taboos towards discussing issues of death and dying, which suggest that we live in a "death-denying" society. However, recent advances like the hospice movement and quest for a good death have brought issues of death and dying into public debate. Older people living in the community can ensure autonomy and ensure that their dying process is in accordance with their values and wishes by signing a living will, discussing end-of-life issues with their doctors or family members or by signing an advance directive, prior to incapacitation.

Chapter 3 reviewed the literature on older people's views on resuscitation and advance care planning and identified the main shortcomings in the literature. The conclusions of the literature review suggested that most of the research conducted on this issue has focused on hospitalised patients. Despite older people in hospitals wishing to participate in resuscitation decision making, they are rarely included. The results suggest that this could be due to issues of competency and problems with its assessment, medical professional's discomfort in discussing these issues and the resuscitation decision made in intensive care where patient participation in decision making is compromised. The timing of the resuscitation decision is therefore crucial when making decisions regarding CPR. Ideally, decisions should be made prior to incapacitation, serious illness or advanced age. The review of the literature suggested that there are wide variations in preferences towards resuscitation and a large degree of variability in older patient's views on who should be responsible for the final decision regarding resuscitation.

Furthermore, literature addressing healthy, community dwelling older people's perspectives on resuscitation decision making in the UK was limited in scope and mainly descriptive. There are very few studies in the UK that deal with advance care planning from a psycho-social perspective (e.g. Phillip & Woodward 1999; Seymour et al, 2004). The literature identified on advance care planning from a psycho-social perspective was mainly conducted in the US, Australia and Israel. Different historical, economic, social and legal factors towards death and dying operate in the UK which may impact on advance care planning. At the time of data collection, advance directives were only legal in the UK under common law. Another limitation of the literature on advance care planning was the heavy emphasis on signing directives. Advance care planning including discussion with doctors and family members were not emphasised in the literature. Finally, various methodological shortcomings in the literature were identified. The studies employ different samples, recruited from different medical settings (acute wards or geriatric units) and at different stages of hospitalisation (during discharge or during hospitalisation) where their views about resuscitation may be different. The method employed by some research of examining the charts of patients who died in hospital and working backwards through their hospital experience, by reviewing and analysing their medical charts and death monitor sheets, does not give any indication how resuscitation decisions are made. Another shortcoming in evaluating these studies is that the extent of illness or disabilities of the samples were unknown or different, with some patients living with chronic or progressive disease. Patients with different illness conditions may hold different views on the appropriateness of resuscitation. Further, some studies using advance care planning use hypothetical scenarios, asking patients to imagine that they had a medical situation or physical or mental dysfunction and then predict whether they would under those circumstances wish to be resuscitated. Participants views in hypothetical situations and when faced with making real decisions for themselves may be different.

The purpose of the second section of Chapter 3 was to introduce a theoretical approach to be used in this research. The broad theoretical approach was social cognitive, and within that framework, the TPB (e.g. Ajzen, 1988) was chosen as offering the most potential for the purposes of this research. The Health Belief Model, Protection Motivation Theory, Social Cognitive Theory and the Stages models were rejected as candidates on the basis that they may not be applicable to the behaviours under consideration (see Chapter 3). The TPB predicts behavior using constructs that could be used to conceptualise the problem and the prediction of advanced care planning and discussion. The model takes into account the rational and deliberate act of decision making, where the individual makes decisions on whether to engage in advance care planning based on an assessment of various factors. As applied to the topic of this thesis, the TPB constructs include an emotional or evaluative component where the individuals take into account their attitudes towards resuscitation decision making, and their attitudes towards death and dying. The theory accommodates the broader social context for the decision, with its inclusion of subjective norms. This takes into account the influence of the family and doctors when making decisions on life prolongation, and more distant societal pressures. Particularly important is the role of perceived behavioural control incorporated in the TPB. This is of particular relevance to the topic under investigation as it was envisaged that control or efficacy to perform the behaviour would strongly influence the behaviour choice. A wish to have control over the dying process by investing in advance care planning may strongly influence intention to perform the behaviour as well as performing the behaviour. Attitude, subjective norms and perceived behavioural control together predict intentions which, in turn, predict behaviour. It was concluded that the TPB had potential to be useful for understanding advance care planning, but criticisms of a social cognitive theoretical approach were noted.

In this thesis both qualitative and quantitative methods were used. A review of the previous literature suggests that both these methods have been used in the study of advance care planning. Given the lack of literature in the UK in the area of advance care planning from a psychological perspective, it was considered appropriate to use both methodologies at this relatively early stage of research on this topic. Chapter 4 provided a case for combining qualitative and qualitative approaches.

In approaching an area which addressed sensitive issues, the researcher was faced with the question of whether older people living in the community would be willing to discuss sensitive issues regarding life prolongation. At the time in which the research was conducted there was little research exploring healthy older people's perspectives of life prolongation in the UK. Therefore to assess the feasibility of the topic under investigation and to explore the factors that healthy community-dwelling older people considered important in advance care planning, a small interview study (study 1, described in Chapter 5) was considered appropriate as an initial method of investigation.

The results of this small-scale study revealed that older people living in the community were willing and able to discuss end-of-life issues and did not find this topic too distressing to discuss. Although a small and unrepresentative group of participants, they raised some interesting themes. For example, they found the issue of advance care planning increasingly relevant as they got older and the realities of life-prolonging medical technologies made it an issue worth seriously contemplating. Participants reported that dying with dignity, quality of life, rights of autonomy and safeguarding against ageism were important factors they considered when thinking about resuscitation decisions. These themes were used to inform and expand the TPB which was used in the next empirical study (see Chapter 6).

The findings of this study confirmed that the TPB might prove useful as the underlying theoretical model. For example, the content analysis suggested that positive attitudes towards death and dying appeared to influence participants to contemplate conducting advance care planning. The importance given to families, religion and legislation, suggested that TPB's variable of subjective norms would predict advance care planning. Living wills were viewed as a way of ensuring that the dying process was in accordance with their wishes, whereas involving the doctor was viewed with ambivalence, because of the heavy 'pro-life' emphasis within medical circles. Therefore, it appeared that issues of control were also considered in making decisions regarding advance care planning.

Therefore, this initial study indicated that end-of-life decision making was relevant to older people living in the community and discussing these issues with them was feasible. Secondly, the findings provided some degree of preliminary support for using TPB as a theoretical model. The findings of this study were used to inform and expand on the next study.

Study 2 (reported in Chapter 6) had three goals. Firstly, past research and the previous study suggests that older people vary in knowledge and views about CPR and advance care planning. It was considered appropriate to use a quantitative approach to elicit these views from a larger sample of older people, before proceeding further with the qualitative approach. Secondly, the initial study indicated that the TPB might prove useful as the underlying theoretical model and so advance care planning was viewed from this perspective. Traditionally, researchers using social cognitive models have used a quantitative approach to study the concepts. Finally, the initial study also suggested that other psychological variables (such as dying with dignity, quality of life, burden and autonomy) may well be important. Therefore the role of additional variables in predicting older people's views towards advance care planning, particularly focusing on discussing end-of-life issues with the doctors and signing living wills were also studied.

A high proportion of older people who participated in the study had knowledge of CPR and the DNAR. However they tended to over estimate the survival rates of CPR, suggesting that despite having knowledge about these life-prolonging measures, this knowledge was not always accurate. Older people had more positive beliefs to discuss end-of-life issues with their family than medical professionals and identified that the reason for this is because they trust family members more than their doctors to make the right decision about their medical care, if they were to be very ill or in a coma.

Study 2 provided moderate support for the TPB. In line with expectations and the TPB, the results from this longitudinal study (n = 120 at time 1 and n = 76 at time 2, 6 months later) indicated that subjective norms and perceived behavioural control predicted intentions. However, contrary to the TPB, attitudes did not predict intentions.

Intentions and perceived behavioural control failed to predict behaviour 6 months later that is, discussing end-of-life issues with the doctor and to signing a living will. However, attitudes towards discussing these issues with their doctors, past behaviour and value for dying with dignity predicted discussing end-of-life issues with the doctor. In the case of signing living wills, favourable attitudes towards end-of-life issues predicted signing a living will. A possible reason to explain the intention-behaviour gap is the sample had highly positive attitudes, and these attitudes had become highly accessible in memory and served as spontaneous guides to behaviour. Discussing end-of-life issues with doctors could prove to be intimidating because the older person may not have thought about the reaction of the doctors to these discussions. Older people with highly positive attitudes may be more likely to persist with their attempts to have this discussion. Attitudes are the only component of the TPB to include an emotional component, and it may be that discussing the highly emotional topic of death and dying is primarily influenced by emotional rather than rational factors.

Past behavioural control failed to contribute to advance care planning, however past behaviour contributed to older people discussing end-of-life issues with their doctors. For someone who had discussed end-of-life issues with their doctors in a previous occasion (past behaviour), a positive response from the doctor may dispel any negative thoughts they may have and they could think that it was easier to discuss these issues again with their doctors. Therefore, it seems that past behaviour may affect perceived behavioural control.

In addition to examining the role of constructs from the TPB, this study investigated the influence of values. The study suggested the importance of dying with dignity in predicting advance care planning. Before proceeding with further quantitative work, given that the predictions of the TPB were not all confirmed, and that other variables such as dying with dignity appeared to play an important role, the next study went back to the qualitative approach. The emphasis of study 2 was on the process of intention formation and performance of behaviour, not on the content or meaning of the constructs in the model. A qualitative approach was considered more appropriate to investigate the meaning older people ascribe to these concepts. Moreover, the sample in study 2 tended to be rather knowledgeable about CPR and, for the most part, had highly positive attitudes towards end-of-life issues. Hence, for study 3 (Chapter 7) a qualitative approach with a carefully selected range of participants was chosen to elicit a wide variety of views.

Study 3 employed eight focus groups (n = 48), composed of participants drawn from a variety of sources designed to result in socioeconomic and religious diversity, were used to elicit a wide variety of views towards life prolongation. The purpose of the study was to understand some of the findings of the previous study and further explore the other psychological concepts that are important to older people when making decisions regarding life prolongation and advance care planning. Therefore the main aim was to provide phenomenological validity and contextualise the findings of study 2.

This study provided explanations for the findings of study 2. Firstly, the results of this study provided further evidence that positive or accepting attitude towards death and dying leads to advance care planning. From interpretative phenomenological analysis of the focus group discussions, it appeared that older people's attitudes towards death and dying often precede the actual cognitive processes involved in making resuscitation decisions. Secondly, the results of this study also provided further evidence for the role of subjective norms in end-of-life decision making. Older people's perceptions about their families' attitudes towards death and dying influenced the decision to discuss resuscitation decisions with them. Thirdly, the results shed light on the various positions older people developed on the definition of acceptable quality of life based on an assessment of medical condition, physical and mental condition, age and ageism and not being a burden. These themes explained the concepts of dying with dignity used in the previous study and highlighted how these values are formed and the meaning older people ascribe to these concepts. More over, the results highlighted the difficulty of assessing or anticipating quality of life prospectively (i.e., after CPR) and how these assessments can be difficult to make for someone else, which could potentially be important barriers in advance care planning. Finally, personal autonomy or control was an important issue for these older people with regard to conducting advance care planning. Those who valued autonomy and wanted control over the decision making in later life were more likely to conduct advance care planning, while others who did not value control were more likely to defer the decision to their doctors and family members.

The results of study 3 also provided explanations for why older people prefer to discuss end-of-life issues with their family members rather than their doctors. The professional commitment to maintaining life, perhaps at almost any cost, could run counter to the high value placed on quality of life as a basis for making the decision. These results suggest an explanation for the results of study 2 indicating that dying with dignity rather than perceived behavioural control predicted older people discussing end-of-life issues with their doctors. The preference to involve the family in the discussion of life prolongation was based on the premise that families were more able to make the decisions on the individual's behalf, and their involvement would increase the likelihood that a person's wishes were adhered to.

The qualitative findings from study 3 confirmed and strengthened the results of study 2. The qualitative findings suggested explanations and contextualized how older people handle decision making in a realistic, dynamic and complex environment, taking into account the wider social context of resuscitation decision making and advance care planning. The findings also shed light as to why some older people fail to think about advance care planning, because of the negative emotions and denial associated with thinking of their mortality. Therefore a pre-requisite to advance care planning was thinking about and accepting the inevitability of death. Finally, the findings of this study provided further support for older people's preference for discussing their resuscitation preference with their family members.

Study 4 (Chapter 8) aimed to understand resuscitation decision making and advance care setting within a family setting by evaluating and comparing both older people's and their confidants' values towards resuscitation decision making and examining their discussion of life prolongation with each other. From the medical perspective, the role of the family is to aid the clinician to act in the 'best interest of the patient' by informing them about the capacity to benefit and quality of life of the incapacitated patient. Therefore to act on the patient's best behalf, the older person and their family members should have a discussion about life prolongation, so that family members know about the older person's resuscitation preferences and the values they have used to arrive at this decision. The values that older people and their confidants (or family members) use to make resuscitation decisions and discuss life prolongation with each other were also investigated. Since the primary aim of the study was to compare the values both parties hold when making resuscitation and advance care decisions, a quantitative approach was considered more appropriate. In addition, the aim was to recruit a diverse sample of older people with different socio-economic backgrounds. Given the large sample recruited and interviewed (69 older people and 53 of their nominated confidants), it was considered more feasible to analyse the results quantitatively.

The results of study 4 suggested that older people and their confidants use different values when evaluating their attitudes towards CPR, choice of CPR and making decisions on whether to discuss end-of-life issues with each other. Confidants were more likely to have more accepting attitudes towards CPR than their older relatives. Older people's attitudes towards CPR were influenced by gender with women more likely to have opposing attitudes towards CPR, value for family (have resuscitation for the sake of the family) and value for age (the older the patient, the less likely the perceived need for resuscitation). Value for family bears resemblance to the subjective norms concept used in the TPB. In contrast, confidants' attitude towards CPR was influenced by the older persons' autonomy and self-determination. Additionally, older people's choice of CPR was influenced by their attitude towards CPR; those with accepting attitudes were more likely to prefer CPR. In contrast, confidants' choice of CPR was influenced by their experience of hospitalisation over the past 5 years - those hospitalized were more likely to choose resuscitation. The results suggest that often there was a misunderstanding between older people and their confidants on whether a discussion of advance care planning had actually taken place. Older people and their confidants were more likely to discuss life prolongation with family members if they had positive attitudes towards death and dying. Confidants in addition were more likely to discuss life prolongation with their family members if they held the value of quality of life as important. Finally, the results suggest that agreement between pairs of confidants and older persons on views on CPR and discussion regarding life prolongation was limited.

The results of this study suggested that if surrogate decision making was to be viewed as a way of ensuring patient autonomy and if family members are to act in the patients' best interest, discussions on life prolongation within the family setting should be conducted and moreover be made explicit. Contrary to expectations, confidants' view resuscitation and advance care decision making in different ways to their older relative.

Overall, the thesis has contributed to the understanding of community dwelling older people's perspectives towards resuscitation orders and advance care planning. The original goal of the movement for advance care planning – from the perspective of ethicists and legal scholars – was to assist patients to make treatment decisions in the event of incapacity. The emphasis has been on encouraging patients to sign living wills or advance directives. However, advance directives are difficult to form, communicate and implement (Miles et al., 1996), and patients typically do not sign advance directives. The findings of this research suggest that one possible answer to the lack of advance directives is the traditional conceptual framework underlying advance care planning and the use of advance directives not being rooted in the needs and experiences of the patient. Traditionally, advance care planning was thought to help people prepare for treatment decisions in time of incapacity, to be based on the ethical principle of autonomy, and to focus on completing written advance directives within the context of the patient-physician relationship. However, the findings suggest that from the older person's perspective, the primary goal of advance care planning is more commonly preparing psychologically for death and dying. Therefore accepting attitudes towards death and dying contributed to advance care planning, and/or contemplating conducting advance care planning. This planning is also influenced by personal relationships, is a social process and occurs within the context of family and loved ones. Advance care planning can help patients prepare for death which, from the older persons' perspective, tends to mean helping them achieve a sense of control, relieving burden on loves ones, and strengthening relationships at the end of life. The findings from this thesis suggest that advance care planning should be conceptualized as a process of communication, and advance directives should be viewed as an assisting device embedded in the advance care planning process (Emanuel et al, 1991; Miles et al., 1996; Singer et al., 1998). The emphasis on advance care planning should therefore be on preparing for dying, taking into account the families' views and ensuring that older people feel in control over their dying process.

9.3 Combining qualitative and quantitative methods

Combining both quantitative and qualitative methodologies was considered appropriate for this relatively new research topic, and contributed more to the understanding of older people's perspectives towards resuscitation decision making and advance care planning than using only one approach. As suggested in the earlier section, the findings of each study were used to inform the design of each successive study. Study 1, using a qualitative methodology, revealed various factors which older people consider when making decisions to conduct advance care planning, which was incorporated in a quantitative study (study 2), employed to test and expand the TPB to explain older people's intentions and behavior with regard to advance care planning. Study 3, using a qualitative approach served to explain the findings of study 2 and finally study 4, using a quantitative approach explored and compared older people's and confidants' views on resuscitation and advance care planning. Alternating between qualitative and quantitative methods helped understand both the content and process of advance care planning. Mixing both methods strengthened the credibility of the research findings, increased the validity of understanding of older people's views towards advance care planning and provided a means of triangulation. Further, this methodology helped the researcher elicit the views of a wide variety of participants from different socio-economic backgrounds who may have had different values or attitudes towards issues of death and dying.

Additionally, mixing methods helped address various criticisms and shortcomings of using the social cognitive approach. Critics have proposed that social-cognitive models do not provide an adequate description of the way in which people make decisions (see Conner & Norman, 1995) and the emphasis of the models is more on process rather than content. This research addressed both the process (in study 2) and the content (i.e., meaning) of the variables (in study 3) contributing to advance care planning.

Another criticism of studies using the social cognitive approach is that it relies upon questionnaires which presuppose that cognitions are pre-existing entities waiting to be retrieved by questionnaire items. Critics of this approach have also suggested that social cognitive models do not allow for contextual variables which may influence social cognitions (e.g. Marks, Murray, Evans & Willig, 2000). In this research, the use of a qualitative approach, particularly the focus groups study, allowed the researcher to gauge how older people make resuscitation decisions and think about advance care planning taking into account the wider social and cultural context. Examples of these wider social contextual factors include living in a 'Death denying' culture and more recent trends towards a more accepting attitude towards death, and the 'Right to life' movement which influences resuscitation and advance care planning decisions. Real-life decision making is bound by a social context including contemporary older people's views about ageism and being a burden in society. Given that advance care planning is a process influenced by the broader social context as well as individual cognitions, involving contextual factors was considered essential and was achieved in part by the qualitative aspects of this research.

Both content analysis and the Interpretative Phenomenological Analysis (IPA) were used in this research. Content analysis involves identification of important themes and patterns in the data, assuming that the themes are already in the data, while IPA assumes that patterns, themes and categories emerge from the data. Despite the marked differences between both these qualitative approaches (a detailed discussion in chapter 4), the findings of both the studies (study 1 & 3) resulted in fairly similar results which strengthens the confidence in the findings. The confirming findings using both methods, was thereby viewed as a form of triangulation.

Combining both qualitative and quantitative methods was not without its shortcomings. The researcher has to develop expertise in both methodologies, which is challenging. However, in the process of acquiring this expertise there were opportunities for cross-fertilisation and important aspects of one methodology were applied to the other. Therefore, the research tended to use more reflexivity in the quantitative studies, with an emphasis on understanding how participants make sense of their reality. In the case of qualitative methods, not only was a rich contextual account of participants' experience provided, but attempts were made to link and apply the findings to theory. That is, some of the themes that emerged in the qualitative analysis could be mapped onto constructs from the TPB and this helped in the thematic interpretation. For example, the focus group study suggested the theme of involving doctors and family members in advance care planning. By mapping this theme onto the TPB's construct of perceived behavioural control, the involvement of doctors was viewed as losing control or lack of volitional control, whereas involving families was construed as retaining an element of control in the decision making process at the end of life.

Although using a combination of qualitative and quantitative approaches was generally viewed as beneficial, possible weaknesses should also be considered. It is possible that if only one methodology had been followed, the research could have moved further along, however this would have involved compromising on the confidence of the findings. It is also likely that, by concentrating on only one methodology, the researcher would have become more of an in-depth expert in that one method, at the expense of breadth of knowledge of psychological methods. Therefore, in all, the advantages of the combined methodological approach were viewed as outweighing the disadvantages.

9.4 The appropriateness of the Theory of Planned Behaviour

The TPB was a good choice for explaining older people's views on resuscitation and advance care planning, particularly when additional variables were added to the model. The model acted as a framework to guide the design and interpretation of the results. Subjective norms or normative beliefs and perceived behavioural control were influential in predicting whether a person intended to conduct advance care planning. Attitudes towards advance care planning failed to predict intentions. However, attitudes towards death and dying predicted whether an older person conducted advance care planning. Additional values, such as dying with dignity, quality of life, ageism and burden predicted advance care planning. Older people who value quality of life, do not wish to be a burden to their families and want to die with dignity, were more likely to sign living wills, and to discuss end-of-life issues with their doctors or family members.

Reviews of studies using the TPB have suggested that TPB variables account for a relatively small proportion of the variance in explaining intentions and behaviour (see Godin & Kok, 1996, Armitage & Conner, 2000). Additional variables, particular to the behaviour being investigated, have been used to explain portions of the remaining variance (see Rutter & Quine, 2002). In this research, the expanded model taking into account values particular to advance care planning, such as the role of quality of life, burden and ageing added to the predictive value of the TPB.

Attitudes towards death and dying, though not specifically incorporated in the TPB contributed to older people thinking about end-of-life issues and directly to conducting advance care planning. These attitudes towards death and dying bear resemblance to the pre-contemplation stage used in the stages of change model. Therefore, older people with accepting attitudes towards death and dying were more likely to think about whether they should conduct advance care planning.

Thus, the TPB acted as a useful framework in which older people's perspectives towards advance care planning can be formulated. However, the importance of attitudes towards death and dying suggests that the transtheoretical (or stage of change) model of Prochaska & DiClemente (1982), might be a useful way to approach the process of the formation of the constructs in the TPB. That is, before a person can have an attitude toward , say, CPR or advance care planning, they must have already contemplated their own death and dying and have an accepting attitude that permits them to think further about their end-of-life care. To understand the views of individuals less interested in the topic of this thesis than those who participated in these studies, the stage of change model may be a useful way to categorize them with regard to the extent to which they are willing to discuss and plan for their death and dying. Therefore, the TPB can be viewed as a useful model, particularly when augmented by additional variables identified in this research, for those older people willing to consider their end-of-life care. For those less willing, a model such as the transtheoretical model would more appropriate.

9.5 Limitations and directions for future work

Research on life prolongation involved confronting some deep seated ethical issues, as it involves asking participants to contemplate death and dying, which are often issues that healthy people do not consider routinely. Concerns regarding the ethics of asking people to talk about these sensitive issues were paramount. It would be unethical to force people to think about death and dying, or issues of life prolongation, unless they themselves were willing to think about these issues. Therefore utmost care was taken to ensure that all participants were aware of the purpose of the research, and participants were given the option of withdrawing from the study at any stage. The findings and interpretation of this research are therefore limited by our inability to evaluate the attitudes of those who refused to participate in the study. Those who did not participate in the study perhaps held the belief that death is a very distressing subject, and such a group was not represented in these studies. This was an unavoidable weakness of both this research and other research on this sensitive issue.

Nevertheless the studies reported here have produced interesting and important findings. Although the limitations relevant to each study have already been mentioned in previous chapters, there are a number of overarching limitations to be noted here. The first overarching limitation was the unrepresentativeness of the samples studied. The samples used in this study were self-selecting and many individuals belonged to ongoing groups suggesting that they may have had more sociable, outgoing dispositions and may have different views compared to more isolated individuals not represented in this research. Further, the samples used in the studies, particularly studies 1 & 2, were quite knowledgeable about end-of-life issues and advance care planning and a large proportion of them had conducted advance care planning previously. Studies 3 & 4 approached a wide variety of sources to target participant with various levels of knowledge and differing perspectives on end-of-life care. However the samples were recruited from S.E. England and tended to belong to the young-old cohort, were rather well educated and from a relatively high socio-economic background. In study 4, it was noticeable that interviewees from lower socio-economic groups were less inclined to think conceptually about the topic or to elaborate on their views.

A second limitation is that many of the participants were recruited predominantly from one generation or age cohort. The responses represent the views of a cohort composed of a generation of older people, many of whom would have gone through the experience of World War 2 and lived through an age when premature death from acute illness was still quite common. They would thus in some cases have seen death at close hand; and many would have encountered it at a personal level. There may therefore have been a cohort effect resulting from the unique historical and other contextual influences for this generation. Attitudes towards death and dying appear to be shifting in younger generations to more open discussion of such topics as assisted suicide, so the findings from this thesis may be limited to understanding how our current older people view advance care planning, specifically decisions about CPR and the DNAR.

A third overarching limitation was the focus on CPR and the DNAR at the expense of close examination of other life-prolonging technologies. The spectrum of research into older people's views on end-of-life care and life prolongation is vast. However this thesis specified that it would only address healthy community dwelling older people's perspective towards CPR and the DNAR. This research provides a basic understanding of older people's views on CPR and related advance care planning, and future research can build on it in a number of ways, including the examination of other decisions about end-of-life care. The present research evaluated older people's perspective on CPR in particular. Study 4 suggested that attitudes towards CPR and other life prolonging medical technologies, such as artificial feeding and ventilation are different. An interesting area to develop and investigate is whether older people use the same values to evaluate other life prolonging medical technologies.

In addition to addressing the above limitations, there are many other possible directions for future research. Future studies could explore variations resulting from wider SES range, educational range and ethnicity. It is possible that views towards resuscitation and advance care planning would be different if these older people were older, closer to death and/or living with a terminal illness. The absence of culturally diverse participants limits generalisability of the findings to ethnic minorities and other cultural groups. It would also be interesting to explore the role of religiosity and particular religious groups (e.g. Christian, Jewish, Moslem and non religious people) with regard to life prolongation and advance care planning.

Particularly relevant and interesting, given the social and legal climate in the UK, would be for future studies to investigate proxy decision making within the family setting and how key decision makers or (confidants) make decisions with or without discussions about life prolongation. Perhaps a further direction for future work would be to try to do case studies of families who have actually had to make such proxy decisions to determine the factors that influenced their decisions and the difficulties that they encountered. This may help in understanding the key factors which determine proxy decisions and also how the experience of proxy decision making may have changed their views on the subject. More research involving entire families and involving younger family members is also needed to understand the extent of disagreements and negotiations regarding life prolongation within the family setting.

A useful direction for future research would be to determine the degree to which medical professionals use the same principles as those identified here for older people and their family members. More effective discussions will occur where all parties are using similar principles, even if they hold different positions with respect to those principles. Research has also suggested that older people are more likely to initiate conversations on end-of-life care if their doctors bring up these conversations (e.g. Emanuel et al., 1991). It would be interesting to gain some understanding of medical professionals' views on discussing life prolongation with healthy older people living in the community.

9.6 Implications for practice

Current CPR guidelines are vague about the important practical issues of how advance care planning should be facilitated. Despite the publication of these guidelines, little is known about the complexities and risks of resuscitation decisions for older people and their perspectives on the involvement of doctors and family members. Findings from this thesis contribute to understand the needs of older people when making these crucial decisions and in improving practice in end-of-life decision making.

Traditionally, end-of-life decision making, including decisions on life prolongation, has been within the paradigm of palliative care. There is a recognised need to avoid overburdening seriously ill patients and denying them the options at the end of life. At the same time, deeply enshrined in health and social legislation, is the patient's right to autonomy or choice based on their own values and morals. Therefore these decisions need to be made prior to hospitalisation, where making decisions prospectively maybe difficult for older people, especially when they are in good health and cannot predict the circumstances of their death.

The present research, and previous studies (e.g. Seymour 2004), indicates that advance care planning is optimal when conceptualised as a review between older people, their doctors and family members about life prolongation. At the community level, education about resuscitation and the ways in which advance directives can be established would be helpful. Moreover, discussions regarding life prolongation could be conducted around assessments of the positions on values such as ageism, and being a burden, of all the parties to the discussion, rather than attempting to arrive at definite decisions regarding use or not use of life prolonging technologies. Interventions educating older people to think about these issues should be developed to meet the needs of the ageing population. The impetus at the community level should not be on making decisions regarding life prolongation, but on education regarding resuscitation (including its efficacy and how medical professionals make these decisions) and the importance of advance care planning (providing them all three options - discussing life prolongation with doctors, family members and or signing living wills and getting them to consider the option that is most appropriate for them).

Previous research from the US has suggested that low intensity educational interventions (such as written material or videotapes) increase the use of advance directives (see Patel et al., 2004). In the UK, the BMA along with the Resuscitation Council has designed a model CPR brochure to be used when patients are admitted into the hospital to inform them about resuscitation policy. Perhaps a similar brochure or leaflet can be used to educate older adults at the community level. There are various brochures available for specific groups, such as the Alzheimer's Society, the British Heart Foundation and Age Concern, and the Voluntary Euthanasia Society has documents about living wills. However, there is a need for basic CPR education at the community level for older people, specifically discussing advance care planning.

Making resuscitation decisions, even for those who are contemplating these issues can be difficult. The findings of this study can be used to help older people think about these issues. As suggested in Chapter 7, older people can think of this decision in terms of quality of life – the importance of physical and mental function, the importance of age, being a burden and the attitudes of their significant others towards death and dying. The importance of being in control and having their autonomy versus deferring the decision to others, either medical professionals or family members can be highlighted in interventions. Our experience in conducting this research suggests that small discussion groups or groups involving older adults and family members for supportive discussion of issues of life prolongation and advance care planning are well received. Perhaps community based interventions could follow a similar model.

The importance of an accepting attitude towards death and dying in advance care planning has been highlighted in this thesis. These attitudes are harder to target, however media programmes can help present more positive images of death and dying and change attitudes towards death and dying. More over programmes on the television or radio can help bring these issues into the limelight.

Older people have their own values and experiences, willingness and ability to talk openly about death and dying. Taking into account these values are an important way in which health professionals can help the individual and their families feel they are in control. Enabling people to become involved in decision making requires sensitivity to personal and cultural values, empathy and an ability to empower people to make choices regarding the care they wish for. If older people make an informed choice to not conduct advance care planning, and leave the decision to family members or their doctors, the right to autonomy is still preserved.

Finally, there is also a need to disseminate the findings of this research and other studies to medical professionals. The curriculum for training medical professionals tends to be limited with regard to communication skills around end-of-life care. The importance of holding three-way discussions involving the medical professional, the older person, and their confidant, has only recently been recognized and was confirmed in the present research (Adelman & Greene, 2001; Beisecker, 1989; Greene, Majerovitz, Adelman & Rizzo, 1994). More training to increase medical professionals' skills and confidence to conduct these sensitive discussions would be valuable.

9.7 Implications for policy

The findings of this study are topical and timely. Since data collection, the House of Commons and the House of Lords passed the Mental Capacity Bill, 2004. The Mental Capacity Bill is designed to protect people who cannot make their own decisions in appointing friends or relatives to manage their affairs if they become mentally incapacitated. The Bill impinges on this study insofar as an Act will give statutory effect to advance directives or living wills and specifies the principles on which incapacitation should be assessed . An 'advance decision' made by a person after he/she has reached 18, and when he/she has capacity to do so, will apply at any later time and in such circumstances as he/she may specify, even if at that time he/she lacks capacity to consent to the carrying out or continuation of the treatment.

The legislation in the UK on advance directives is still in the early stages of development. It remains unclear at this stage whether this piece of legislation will give an impetus to older people signing living wills. However, lessons from the US suggest that this is unlikely to happen (e.g. Phillips et al., 1996). More importantly, the findings of this study suggests that there is a preference for older people living in the community to involve their family members and/or defer this decision to their doctors and family members, rather than sign living wills. No doubt that this act will raise the profile of the issue of advance care planning; but education campaigns and interventions taking into account psychological predictors (such as those revealed in this research) are needed in addition to changes in legislation.

The new Mental Capacity Bill suggests that besides financial matters, the powers of the Lasting Power of Attorney extends to giving and refusing consent to the carrying out and continuation of a treatment of a person, however it does not authorize the giving or refusing consent or continuation of life sustaining treatment, unless the advance directive contains expressed provision to that effect. The findings of this study have repeatedly suggested the preference for involving a family member and the concerns of involving families in CPR decision making. It remains unclear how the family will make decisions on behalf the patients when legal guidelines suggest the contrary. There is hence a need to recognize that the family will be heavily involved in these decisions. More research and legal clarification is warranted on proxy decision making.

9.8 Final Reflections

Personally, this piece of work has been challenging and a learning experience. Prior to beginning this thesis, I had not given much thought to issues of death and dying and the emotional components to making decisions of life and death. I spent the formative years of my life in India, where death is looked on as a part of life and a belief in life after death is prevalent. Life prolongation options are not routinely presented to older people and there are few life support units in India, mainly in larger cities and towns and mainly offered in accident cases, where the patients are usually younger, or to patients recovering from surgery. There is no universal CPR policy that exists and CPR is only initiated after careful consideration. Being young and healthy and having lost my grandparents at a young age, without any sort of life prolongation, I had not considered some of the issues that this thesis addresses.

In the course of collecting data, analysing results and writing this thesis, I learnt to appreciate the enormity of the situation and also relate to the older people on how hard and complex these decisions were and also appreciated how important it was for them to make arrangements for life when incapacitated. In various ways, despite the age and cultural differences, I could empathise with the 'get on with life and not think about death' attitude of some of the participants. In other respects, having witnessed the resuscitation process, spending time with the resuscitation team at the hospital and having read medical documentation of the lack of success rates and the damaging effects of resuscitation, I felt an urgency to get participants to think about these issues. I personally, did not have any 'pro-life', 'right to die' or any other affiliations, but learnt to accept that this was a personal choice based on personal, family and cultural values. In various ways, this experience has made me respect and accept that each person and each family have their own ways of dealing with death and making provisions for end-of-life care.

References

Adelaman, R., & Greene, M. (2001). *Multi-Party Interactions in Geriatric Medical Encounters.* Conference on 'Exploring Older Patient Encounters with Health Care Providers: Innovations in Research, Practice and Medical Education', St. Louis, Missouri, 22nd to 25th May, 2001.

Addington-Hall. J., Fakhoury, W. & McCarthy, M. (1998). Specialist palliative care in non-malignant disease. *Palliative Medicine*, 9, 295-305.

Age Concern (1999). *The future of health and care of older people.* Age Concern England: London.

Age Concern England (1999) The Millennium papers: Values and attitudes in an aging society. Glasgow: Bell & Bain Ltd.

Age Concern England (2000). *Turning your back on us- Older people and the NHS.* London: Age Concern.

Aikman, P.J., Thiel, E.C., Martin, D.K. & Singer, P.A. (1999). Proxy, health, and personal care preferences: implications for end-of-life care. *Cambridge Quarterly of Healthcare Ethics*, 8, 200-210.

Ajzen, I. (1985). From intentions to actions: A theory of planned behaviour. In J. Kuhl & K. Bechman (eds.), *Action-control: From Cognition to Behaviour* (pp. 11-39). Heidelberg: Springner.

Ajzen, I. (1988). *Attitudes, Personality and Behaviour.* Milton Keynes: Open University Press.

Ajzen, I. (1991). The Theory of Planned Behaviour. *Organisational Behaviour & Human Decision Processes,* 50, 179-211.

Ajzen, I. (2002). Residual effects of past behaviour on later behaviour: Habitual and reasoned action perspective. *Personality & Social Psychology Review*, 6, 107-122.

Ajzen, I., & Fishbein, M. (2004). Questions raised by a reasoned action approach: Comment on Ogden (2003). *Health Psychology, 23,* 431-434.

American Psychological Association (2000). *Report on assisted suicide and end-of-life decisions.* Retrieved on 15th January, 2002, from http://www.apa.org/pi/aseol/introduction.html

Aries, P. (1977). *The hour of our death.* London: Allen Lane.

Armitage, C. & Conner, M. (1999). The theory of planned behaviour: assessment of predictive validity and 'perceived control'. *British Journal of Social Psychology,* 38, 35-54.

Armitage, C. J., & Conner, M. (2001). Efficacy of the theory of planned behaviour: A meta-analytic review. *British Journal of Social Psychology, 40,* 471 - 499.

Bagozzi, R.P. (1981). Attitudes, intentions and behaviour: A test of some key hypothesis. *Journal of Personality and Social Psychology,* 41, 607-627.

Bagozzi, R.P. & Yi, Y. (1989). The degree of intention formation as a moderator of the attitude-behaviour relationship. *Social Psychology Quarterly,* 52, 266-279.

Bagozzi, R.P. (1993). On the neglect of volition in consumer research: A critique and proposal. *Psychology & Marketing,* 10, 215-37.

Bandura, A. (1977). Self- efficacy: Towards a unifying theory of behavioural change. *Psychological Review,* 84, 191-215.

Bandura, A. (1986). Social foundations of thought and action. Englewood Cliffs, NJ: Prentice-Hall.

Bandura, A. (1992). On rectifying the comparative anatomy of perceived control: Comments on 'Cognates of personal control'. *Applied and Preventive Psychology,* 1, 121-126.

Bandura, A. (1992). Exercise of personal efficacy through the self-efficacy mechanism. In R. Schwarzer (ed.) *Self-efficacy: Thought Control of Action* (pp.5-21) London: Hemisphere.

Banister, P., Burman, E., Parker, M. & Tindal, C. (1994). *Qualitative methods in psychology: A research guide.* Buckingham: Open University Press.

Bayer, A.J., Ang, B.C., Patmy, M.S.J. (1985). Cardiac arrest in a geriatric unit. *Age and Ageing,* 14, 271-276.

Becker, E. (1973). *The denial of death.* New York: Free Press.

Bedell, S. & Delbanco, T. (1984). Choices about cardiopulmonary resuscitation in the hospital: when do physicians talk with patients? *New England Journal of Medicine,* 310, 1089-1093.

Bedell, S.E., Pelle, D., Maher, P.L. & Cleary, P.D. (1986). Do-not-resuscitate orders for critically ill patients in hospital. *Journal of American Medical Association,* 256, 233-237.

Beisecker, A.E. (1989). The influence of a companion on the doctor-elderly patient interaction. *Health Communication*, 1 (1), 55-70.
Billig, M. (1994). Repopulating the depopulated pages of social psychology. *Theory and Psychology*, 4 (3), 307-335.

Blackhall, L.J. (1987). Must we always use CPR? New England Medical Journal, 317, 1281-1285.

Blackhall, L.J., Frank, G., Murphy, S.T., Michel, V., Palmer J.M. & Azen, S.P. (1999). Ethnicity and attitudes towards life sustaining technologies. *Social Science & Medicine*, 48, 1779-1789.

Blank, R.H. (2001). Technology and death policy: Redefining death. *Mortality*, 6 (2), 191-202.

Blondeau, D., Valoia, P., Keyserlingk, E., Hebert, M. & Lavoie, M. (1998). Comparison of patients' and health care professionals' attitudes towards advance directives, *Journal of Medical Ethics*, 24, 328-335.

Bowker, L; Stewaart, K; Hayes, S; Gill, M. (1998). Do general practitioners know when living wills are legal? *Journal of Royal College of Physicians London*, 32, 351-3.

Bowling, A. (1999). Ageism in Cardiology. *British Medical Journal*, 319, 1353-5

Bradley, E., Walker, L., Blencher, B. & Wetle, T. (1997). Assessing capacity to participate in discussion of advance directives in nursing homes: Findings from a study of the Patient Self-Determination Act. *Journal of American Geriatrics Society*, 45 (1), 79-83.

Branco, K., Teno, J. & Mor, V. (1995). Advanced care panning among nursing home residences prior to the patient self-determination act. *Journal of Health & Social Policy*, 7 (1), 37-52.

Bravo, G., Dubois, M., Paquel, M. (2003). Advance directives for health care and research: Prevalence and correlates. *Alzheimer Disease & Associated Disorder*, 17 (4), 215-222.

British Medical Association. (BMA, 1999). *Decisions relating to cardiopulmonary resuscitation*. A join statement from the British Medical Association, Resuscitation Council (UK) and the Royal College of Nursing. British Medical Association: London.

British Medical Association. (BMA, 2000). BMA rejects age discrimination and reaffirms its good practice guidance on resuscitation. Retrieved on 17th May, 2002, from http://www.bma.org.uk/.

British Medical Association (BMA, 2001). A joint statement from the British Medical Association, Royal College Nursing & Resuscitation Council, UK. Decisions relating to cardiopulmonary resuscitation. Retrieved on 17th May, 2002, from http://www.resus.org.uk/pages/drar.htm/

Broadwell, A., Boisaubin, E., Dunn, J. & Engelhardt, H. (1993). Advance directives on hospital admission: A survey of patient attitudes. *Southern Medical Journal*, 86, 165-168.

Brock D. (1996). What is the moral authority of family members to act as surrogates for incompetent patients? *Millbank*, 74, 599-618.

Brown, J.B., Beck, A., Boles, M. & Barrett, P. (1999). Practical methods to increase use of advance medical directives: A randomised control trail. *Journal of General Internal Medicine*, 14, 21-26.

Bruce-Jones, P.N., Roberts, H., Bowker, L., Cooney, V. (1996). Resuscitating the elderly: What do the patients want? *Journal of Medical Ethics*, 22, 154-9.

Bryman, A. (1988). *Quantity and quality in social science.* London: Unwin Hyman.

Burt, R.A. (2003). *End of life care in the ICU: Legal difference.* International Consensus Conference in Intensive Care Medicine, "Challenges in end-of-life care in the ICU", Brussels, 24th-25th April. Retrieved on 15th January, 2005 from http://www.esicm.org/consensus/Burt%20text.htm

Callahan, D. (1993). *The troubled dream of life: Living with mortality.* New York: Simon & Schuster.

CancerBacup. (2003). Should the doctor ever let a patient die? http://www.cancerbacup.org.uk/News/Newsletter/Issue48/Practicalhelp/Shouldthedoctoreverletapatientdie

Caralis, P.V., Davis, B., Wright, K. & Marcial, E. (1993). The influence of ethnic and race on attitudes towards advance directives, life prorogation treatments and euthanasia. *Journal of Clinical Ethics*, 4 (2), 155-165.

Carmel, S. & Mutran, E. J. (1997). Preferences for different life sustaining treatments among elderly persons in Israel. *Journal of Gerontology: Social Sciences*, 52 B, S97-S102.

Carmel, S. (1999a). Life-sustaining treatments: what doctors do, what they want for themselves and what elderly persons want. *Social Science & Medicine*, 49, 1401-1408.

Carmel, S. & Mutran, E.J (1999b). Stability of elderly persons' expressed preferences regarding the use of life-sustaining treatments. *Social Science & Medicine*, 49, 303-311.

Carpiniello, B., Carta, M.& Rudas, N. (1989). Depression among Elderly People: A Psychosocial Study of Urban and Rural Populations. *Acta Scandinavica,* 80 (5), 445-450

Casarett, D., Stocking, C. & Siegler, M. (1999). Would physicians override a do-not-resuscitate order when a cardiac arrest is iatrogenic? A survey. *Journal of General Internal Medicine,* 14, 35-8.

Casebeer, A.L. & Verhoef, M.J. 1997). Combining qualitative and quantitative research methods: Considering the possibilities for enhancing the study of chronic diseases. *Chronic diseases in Canada,* 18 (3), Retrived on 15th Jan uary 2005 from http://www.phac-aspc.gc.ca/publicat/cdic-mcc/18-3/a_e.html

Castle, N.G. (1998) Advance care planning in nursing homes: pre and post Patients Self Determination Act. *Health services research,*

Charlson, M.E., Sax, C.R., MacKenzie, S.D. (1986). Resuscitation: How do we decide? A prospective study of physicians' preferences and the clinical course of hospitalised patients. *Journal of American Medical Association,* 255 (10), 1316-22.

Chiu, H., Li, S. (2000). Advance Directives: A case for Hong Kong. *Journal of the Hong Kong Geriatrics Society,* 10 (2), 99-101.

Cicirelli, V.G. (1997). Relationship of Psychosocial and Background Variables to Older Adults' End of Life Decisions. *Psychology and Ageing,* 12 (1), 72-83.

Clark, D. (1993). *The sociology of death.* Oxford: Blackwell Publishers.

Clark, D. & Seymour, J. (1999). *Reflections on palliative care.* Open University Press, Buckingham.

Clark, L.F. (1994). Social Cognition and Health Psychology. In R. S. Wyer & T. K. Srull (Eds.), *Handbook of Social Cognition* (2nd ed., vol. 2, pp. 239-288). Hillsdale, NJ: Laurence Erlbaum.

Clive, S. (2000). Changing patterns of death and dying. *Social Science & Medicine*, 51, 917-930.

Cohen-Mansfield, J., Droge, J.A. & Billig, N. (1992). Factors influencing hospital patients' preferences in the utilisation of life-sustaining treatments. *Gerontologist,* 32, 89-95.

Collopy, B.J. (1990). Ethical dimensions of autonomy in long-term care. *Generation*, 9-12.

Committee on care at the end of life, Institute of Medicine. (1997). *Approaching death: Improving care at the end of life.* Washington DC: National Academy Press.

Committee on Medical Ethics, British Medical Association (2000). *The impact of the Human Rights Act 1998 on medical decision making.* Retrieved 19th May 2002, from http://www.cirp.org/library/legal/BMA-human-rights/.

Conner, M. & Norman, P. (1996). *Predicting Health Behaviours.* Buckingham: Open University Press.

Conner, M & Norman, P. (1998a) Special issue: Social cognition models in health psychology. *Psychology and Health*, 13, 179-85.

Conner, M & Armitage, C. (1998b). Extending the theory of planned behaviour: a review and avenues for further research. *Journal of Applied Social Psychology, Special Issue,* 28, 1430-1464.

Conner, M. & Sparks, P. (2002). Ambivalence and Attitudes. In W. Stroebe & M. Hewstone (Eds.), *European Review of Social Psychology*, Vol. 12 (pp. 37-70). Chichester: Wiley.

Costello, J. (2002). Do not resuscitate orders and older patients: findings from an ethnographic study of hospital wards for older people. *Journal of Advanced Nursing*, 39 (5), 491-499.

Curtis, J.R., Park, D.R., Krone, M.R., Pearlman, R.A. (2000). Use of medical futility rational in do-not-attempt- resuscitation orders. *Journal of Medical Association*, 273, 124-8.

Damato, A.,Reddy, D., Rusche, P., Ramakrishna, S., Christollersen, G., Gestsis, J., Feinsod, R., Resisner, M, Cost, D, & McCreath, J. (1993). Advance directives for the elderly: A survey. *New Jersey Medicine*, 90, 215-220.

Danis, M., Southerland, L.I., Garrett, J.M. (1991). A prospective study of advance directives for life-sustaining care. *New England Journal of Medicine*, 234 (13), 882-888.

Danis, M., Garrett, J., Harris, R., Patrick, D.L. (1994). Stability of choices about life-sustaining treatments. *Annals of Internal Medicine*, 120, 567-573.

Danis, M., Federman, D., Fins, D., Joseph, J., Fox, E., Kastenbaum et al. (1999). Incorporating palliative care into critical care education: Principles, challenges and opportunities. *Critical Care Medicine*, 27 (9), 2005-13.

Davis, G. & Vincent, J. (1998). Progress report: Religion and old age. *Ageing and Society*, 18, 101-110.

Davis, E. & Higginson, I.J. (2004). *The solid facts: Palliative Care.* Denmark: World Health Organisation Europe. Retrieved on 15th January 2005, from http://www.ilcusa.org/_lib/pdf/facts.pdf

Denzin, N.K. & Lincoln, Y.S. (1994). *Handbook of qualitative research.* London: Sage.

Department of Health. (2001). *Older people's National Service Framework Standards.* Retrieved on 1st December 2004, from www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/OlderPeoplesServices/fs/en

DiClemente, C.C. & Huges, S.O. (1990). Stages of change profiles in outpatient alcoholism treatment, *Journal of Substance Abuse*, 2, 217-35.

Diem, S.J. Lantos, J.D. & Tulsky, J.A. (1996). Cardiopulmonary resuscitation on television: Miracles and misinformation. *New England Journal of Medicine*, 334, 1578-82.

Diggory & Judd. (2000). Advance directives: Questionnaire survey of NHS trust. *British Medical Journal*, 320, 24-25.

Ditto, P.H., Dank, R.M., Houts, R.M., Coppola, K.M., Smucker, W.D., Jacobson, J.A., Fagerlin, A. & Gready, R.M. (2003). Stability of older adults' preference for life sustaining medical treatments. *Health Psychology*, 22 (6), 605-615.

Dobson, R. (1999). Guidelines ignored on resuscitation decisions. *British Medical Journal*, 319, 536.

Doyal, L., & Wilsher, D. (1993). Withholding cardiopulmonary resuscitation: proposal for formal guidelines. *British Medical Journal*, 306, 1593-96

Doyal, L. & Wilsher, D. (1994). Withholding and withdrawing life sustaining treatment in elderly people: towards formal guidelines. *British Medical Journal*, 308, 1689-92.

Dunne, E.A, & Quayle, E. (2001). The impact of iatrogenically acquired Hepatitis C infection on the well-being and relationships of a group of Irish woman. *Journal of Health Psychology*, 6 (6), 679-92.

Ebell, M.H., Becker, L.A., Barry, H.C., Hagen, M. (1998). Survival after in-hospital cardiopulmonary resuscitation: A meta-analysis. *Journal of General Internal Medicine*, 13, 805-816.

Ebell, M., Smith, M.A., Seifert, G.K. & Polinelli, K. (1990). The do-not-resuscitate order: Outpatient experience and decision making preference. *Journal of Family Practice*, 31 (6), 630-636.

Ebrahim, S. (2000). Do not resuscitate decisions: Flogged dead horses or a dignified death? *British Medical Journal*, 320, 1155-56.

Edelmann R.J. (2000). *Psychosocial Aspects of the Health Care Process.* Harlow: Prentice Hall.

Edwards, W. (1954). The theory of decision making. *Psychological Bulletin*, 51, 380-417.

Edwards, W. (1992). *Utility theory: Measurement and applications*. Boston: Kluwer.

Eisemann, M. & Richter, J. (1999). Relationships between various attitudes towards self-determination in health care with special reference to an advance directive. *Journal of Medical Ethics*, 25, 37-41.

Ejaz, F. (2000). Predictors of advance directives in institutionalised elderly. *Journal of Gerontological Social Work*, 33 (4), 67-88.

Eleazer, P.G., Hornung, C.A., Egbert, C.B., Egbert, J.R., Eng, C., Hedgepeth, J., McCann. R., Strothers, H., Sapir, M., Wei, M. & Wilson, M. (1996). The relationship between ethnicity and advance directives in a frail older population. *Journal of American Geriatrics Society*, 44, 938-43.

Ellershaw, J. & Ward, C. (2003). Care of the dying patient: The last hour or days of life. *British Medical Journal*, 326, 30-34.

Elliott , R., Fisher, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.

Emanuel J. & Emanuel L. (1992). Proxy decision making for incompetent patients: an ethical and empirical analysis. *Journal of American Medical Association*, 267, 2067-71.

Emmanuel, L. & Emmanuel, E. (1993). Decisions at the end of life communicated by patients. *Hastings Centre Report*, Sept-Oct, 6.

Emanuel L.L., Emanuel., E.J., Stoeckle, J.D., Hummel, L.R. & Barry, M.J. (1994). Advance directives: Stability of patients' treatment choices. *Archives of Internal Medicine*, 154, 209-217.

Emanuel, L. (2000) How living wills can help doctors and patients talk about dying: They can open a positive, caring approach to death. *British Medical Journal*, 320, 1618-9.

Everitt, B. (1993). *Cluster Analysis.* (3rd edition), London: Edward Arnold

Faucault, M. (1963). *Birth of the clinic.* New York: Random House.

Fazel, S., Hope, T. & Jacoby, R. (1999). Assessment of competency to complete advance directives: validation of the patient centred approach. *British Medical Journal,* 318, 493-497.

Fazio, R.H. (1990). Multiple processes by which attitudes guide behaviour: The MODE model as an integrative framework. In M.P. Zanne (Ed.) *Advances in experimental social psychology* (Vol. 23, pp.75-109). San Diego, CA: Academic.

Feather, N.T. (1982). *Expectations and actions: Expectancy-value models in psychology.* Hillsdale, NJ: Erlbaum.

Feifel, H. (1977). *New meanings of death.* London: McGraw-Hill.

Field, D. (1996). Awareness of modern dying. *Mortality,* 1, 255-265.

Fishbein, M. &Ajzen, I. (1975). *Belief, attitude, intentions and behaviour: An introduction to theory and research.* Reading: MA: Addison-Wisley.

Fishbein, M. (1993). Introduction. In D.J. Terry, C. Gallois & M. McCamish (eds). *The theory of reasoned action: Its application to AIDS-preventive behaviours.* (pp. xv-xxv) Oxford: Pergamon.

Fiske, S.T. & Taylor, S.E. (1991). *Social cognition* (2nd edition). New York: McGraw-Hill.

Flowers, P., Duncan, B. & Frankis, J. (2000). Community, responsibility and culpability: HIV risk-management amongst Scottish gay men. *Journal of Community and Applied Social Psychology,* 10, 285-300.

Flick, U. (2002). *An introduction to qualitative research.* (2nd edition). London: Sage.

Fortner, B.V., Neimeyer, R.A. & Rybarcyk, B. (2000). Correlates of death anxiety in older adults: A comprehensive review. In A.T. Tomer (eds.). *Death attitudes and the older adult: Theories, concepts and application.* Ann Harbour: Taylor and Francis.

Frank, C., Heyland, D.K., Chen, B., Farquhar, D., Myers, K. & Iwassa, K. (2003). Determining resuscitation preferences of elderly inpatients: A review of the literature, *Canadian Medical Association Journal*, 169 (8), 795-9.

Frankl, D., Oye, R.K. & Bellamy, P.E. (1989). Attitudes of hospitalised patients towards life support: A survey of 200 medical inpatients. *American Journal of Medicine*, 86, 645-648.

Frued, S. (1913-53). *Thoughts for the times on war and death.* In collective works (Vol. IV). London: Hogarth Press.

General Accounting Office (GAO, 1995). *Patient Self-Determination Act: Providers offer information on advance directives, but effectiveness uncertain.* Washington, D.C.: United States General Accounting Office (GAO/HEHS-95-135).

Ghusn, H.F., Teasdale, T.A., Jordan, D. (1997). Continuity of do-not-resuscitate orders between hospitals and nursing home settings. *Journal of American Geriatrics Society*, 45, 465-469.

Glaser, B.G. & Strauss, A.L. (1968). *Time for Dying.* Chicago: Aldine.

Glick, H.R. (1992). *The right to die.* New York: Columbia University Press.

Godin, G. & Kok, G. (1996). The theory of planned behaviour. A review of its applications to health related behaviours. *American Journal of Health Promotion*, 11, 87-98.

Godin, G., Valois, P. & Lepage, L. (1993). The pattern of influence of perceived behavioural control upon exercising behaviour: An application of Ajzen's theory of planned behaviour. *Journal of Behavioural Medicine*, 16, 81-102.

Goldstein, M.K., Vasllone, R.P., Pascoe, D.C. & Winograd, C.H. (1991). Durable power of attorney or health care: Are we ready for it? *Western Journal of Medicine*, 155, 263-268.

Gollwitzer, P. & Brandstatter, V. (1997). Implementation intentions and effective goal pursuit. *Journal of Personality and Social Psychology,* **73,** 186-199.

Gordin, M. & Singer & P.A. (1995). Decisions and care in the end of life. *Lancet,* 346 (896), 163-7.

Gordon, N.P., Williamson, S. & Lawler, P.G. (1998). As seen on TV: Observational study of cardiopulmonary resuscitation in British television medical dramas. *British Medical Journal,* 317, 780-3.

Gordon, N.P. & Shade, S.B. (1999). Advance directives are more likely among seniors asked about end-of-life care preferences. *Archives of Internal Medicine,* 159 (7), 701-705.

Grade, G.E., Addington-Hall, J. & Todd, C.J. (1998). Place of death and access to home care services: are certain patient groups at a disadvantage? *Social Science and Medicine,* 47 (5), 565-79.

Greco, P.J., Schulman, K.A., Lavizzo-Mourey, R. & Hansen-Flaschen, J. (1991). The patient Self-Determination Act and the future of advance directives. *Annuals of Internal Medicine,* 115, 263-643.

Greene, M., Majerovitz, S., Adelman, R. & Rizzo, C. (1994). The effect of the presence of a third person on the physician-older patient medical interview. *Journal of American Geriatric Society,* 42 (4), 413-419.

Guaraccia C. & Zautra, A. (1989). Use of Confidant Reports to assess the affective state of older adults. *Clinical Gerontologist,* 9 (2), 68-71.

Gunasekera, N.P.R., Tiller, D.J., Clements, L.T. & Bhattacharya, B.K. (1986). Elderly patients' views on cardiopulmonary resuscitation. *Age and Ageing,* 15, 364-8.

Hammesley, M. (1989). *The dilemma of qualitative methods.* London: Rutledge & Kegan Paul.

Hammersley, M. (1992). Deconstructing the qualitative-quantitative divide. In J. Brannen (ed). *Mixing quantitative research* (pp. 39-55). Aldershot: Avebury.

Hammesley, M. (1993). *Social Research: Philosophy. Politics and practice.* London: Sage.

Hammersley, M. (1995). *The policies of social research.* London: Sage.

Hammersley, M. (1996). The relationship between qualitative and quantitative research: Paradigm loyalty versus methodological eclecticism. In J.T.E.

Richardson (Eds.) *Handbook of qualitative research methods for psychology and the social sciences*. Leicester: BPS Books.

Hanson, L.C. Danis, M. & Garrett, J. (1997). What is wrong with end-of-life care? Opinions of bereaved family members. *Journal of American Geriatrics Society*, 45, 1339-1344.

Harding, S. (1987). Introduction: Is there a feminist method? In S. Harding (Ed.), *Feminism and methodology*. Bloomington, IN: Indiana University.

Hardwig, J. (1991). The problem of proxies with interest of their own: towards a better theory of proxy decisions. *Journal of Clinical Ethics*, 4, 41-6.

Harding, S. (1987). *Feminism and methodology*. Milton Keynes. Open University Press.

Harrison, J.A., Mullen, P.D. & Green, L.W. (1992). A meta-analysis of studies of the health belief model with adults. *Health Education Research*, 7, 107-16.

Henwood, K. & Pidgeon, N. (1992). Qualitative research and psychological theorizing. *British Journal of Psychology*, 83, 97-111.

Heller, R.F., Stelle, P.L., Disher, J.D. ,Alexander, H.M. & Dobson, A.J. (1995). Success of cardiopulmonary resuscitation after heart attack in hospital and outside hospital, *British Medical Journal*, 311, 1332-6.

Hickey, T. (1988). Self-care behaviour of older adults. *Family and community health*, 11, 23-32.

Higginson, I., Astin, P. & Dolan, S. (1998). Who do cancer patients die? Ten-year trends in the place of death of cancer patients in England. *Palliative Medicine*, 12, 353-63.

Higginson, I, Priest, P. & McCarthy, M. (1994). Are bereaved family members a valid proxy for a patient's assessment of dying? *Social Science & Medicine*, 38 (4), 553-557.

High, D.M. (1988). All in the family: Extended autonomy and expectations in surrogate health care decision making. *The Gerontologist*, 28, 46-51.

High, D.M. (1993a) Advance Directives and the elderly: A study of intervention strategies to increase use, *Gerontologist*, 33 (3), 342-349.

High, D.M. (1993b). Why are elderly people not using advance directives? *Journal of Ageing and Health*, 5 (4), 495-515.

Hill, M.E., MacQuill, G., Forsyth, M., Heath, D.A. (1994). Cardiopulmonary resuscitation: who makes the decision? *British Medical Journal*, 308, 1677.

Hoflin, B.F. (1988). Autonomy in long term care: Background issues and a programme response. *The Gerontologists*, 28, 3-9.

Hoffman, J.C., Wenger, N.S., Davis, R.B., Teno, J., Conner, A.F. & Desbeiens, N. (1997). Patients preferences for communication with physicians about end-of-life decisions. *Annals of Internal Medicine*, 127, 1-12.

Holt, J. (2002). Withdrawing treatment: ethical issues at the end of life. In K. Kendrick, D. Clarke, & J. Flanagan. (Eds). *Advance Nursing Practice in Cancer Care Ethics*. Basingstoke: Palgrave.

Hood, R.W. Jr., & Morris, R.J. (1983). Towards a theory of death transcendence. *Journal for the Scientific Study of Religion*, 16, 169-178.

House of Commons. (2004). Mental Capacity Bill. Retrieved on 15th January from http://www.publications.parliament.uk/pa/cm200304/cmbills/120/2004120.pdf

Howarth, G. (1998). Just live for today: living, caring, ageing and dying. *Ageing & Society*, 18, 6, 673-89.

Ingham, R., Woodcock, A. & Stenner, K. (1992). The Limitations of Rational Decision-Making Models as Applied to Young People's Sexual Behaviour. In Aggleton, Peter, Hart, Graham and Davies, Peter. (eds). *AIDS: Rights, Risk and Reason*. London: Falmer Press.

Inman, L. (2002). Why community based older adults do not discuss their wishes. *Journal of Gerontological Nursing*, 28 (9), 40-46.

Janz, N.K. & Becker, M.H. (1984). The health belief model: A decade later. *Health Education Quarterly*, 11, 1-47.

Johnston, S.C., Pfeifer, M.P., McNutt, R. (1995). The discussion about advance directives: Patients and physicians opinions regarding when and how it should be conducted. *Archives of Internal Medicine*, 155, 1025-1030.

Johnston, S.C., Pfeifer, M.P. and the End-of-Life study group. (1998). Patient and physicians roles in end-of-life decision making. *Journal of General Internal Medicine*, 13, 43-45.

Jonas, K. (1993). Expectancy-value models of health behaviour: An analysis by conjoint measurement. *European Journal of Social Psychology*, 23, 167-83.

Jones, R. (1995). Why do qualitative research? *British Medical Journal*, 311, 2.

Jonsson, P.V., McNamee, M., & Campion, E.W. (1988). The do-not-resuscitate order: A profile of its changing use. *Archives of Internal Medicine*, 148, 2373-75.

Kastenbaum, R. (2000). *The Psychology of Death.* (3rd edition) London: Springer Publishing Company Inc.

Katz, J. & Sidell, M. (1994). *Easeful death: Caring for dying and bereaved people.* London: Hodder & Stoughton Educational.

Keatinge, R.M. (1989). Exclusion from resuscitation. *Journal of the Royal Society of Medicine*, 82, 402-5.

Keith, P.M. (1983). Patterns of assistance among parents and the childless in very old age: Implications for practice. *Journal of Gerontological Social Work,* 6 (1), 49-59.

Kelner, M. (1993a). Advance directives: the view of health care professionals. *Canadian Medical Association*, 148, 1331-8.

Kelner, M.J. & Bourgeault, I.L. (1993b). Patient control over dying: Response of health care professionals. *Social Science & Medicine*, 36 (6), 757-765.

Kelner, M. (1995). Activist and delegates: Elderly patients' preferences about control at the end of life. *Social Science and Medicine*, 41 (4), 537-545.

Kendrick, K & Robinson, S. (2002). *Their rights: Advance directives and living wills explored.* Age Concern England: London.

Khaw, K (1999). How many, how old, how soon? *British Medical Journal*, 319, 1350-2.

Kitzinger, C. J. (1995). Qualitative research: Introducing focus groups. *British Medical Journal*, 311, 299-302.

Klessig, J. (1992). The effect of values and culture on life support decisions. Cross-cultural medicine- A decade Later (Special Issue). *Western Journal of Medicine*, 157, 316-322.

Koenig, H. G., Parkerson, G. R., & Meador, K. G. (1997). Religion index for psychiatric research. *American Journal of Psychiatry*, 153, 885-886.

Kouwenoven, W.B., Jude, J.R., Knickenbocker, G.G. & Baltimore, M.S.E. (1960). Closed-chest cardiac massage, *Journal of the American Medical Association*, 173, 94-7.

Krippendorff, K. (1980). *Content Analysis: An introduction to its methodology*. London: Sage.

Krueger, R.A. & Casey, M.A. (2000). *Focus Groups: A practical guide for applied research*. London: Sage.

Krumholz, H.M., Philips, R.S., Hamel, M.B., Teno, J.M., Ballamy, P. & Broste, S.K. (1998). Resuscitation preferences among patients with severe congestive heart failure: results from the SUPPORT project. *Circulation*, 98, 648-55.

Kubler-Ross, E. (1969). *On death and dying*. Tavistock Publications: London.

Landi, G. (1996). No to DNAR orders in acute stoke: Commentary. *Lancet*, 347 (9005), 848.

Landon, L. (2000). CPR: When is it acceptable to withhold it? And a hospital survey of 'Not for CPR' orders. *Age and Ageing*, 29 (S1), 9-16.

Levin, J.R., Wenger, N.S., Ouslander, J.G., Zellman, G., Schnelle, J.F. & Buchanan, J.L. (1999). Life-sustaining treatment decisions for nursing home residents: who discusses, who decided and what is decided. *Journal of American Geriatrics Society*, 47, 82-87.

Liddle, J., Gilleard, C. & Neil, A. (1994). The views of elderly patients and their relatives on cardiopulmonary resuscitation. *Journal of Royal College of Physicians London*, 28, 228-9.

Lipton, H.L. (1988). Do not resuscitate orders in a community hospital: Incidence, implications, and outcomes. *Journal of the American Medical Association*, 256 (9), 1164-69.

Lloyd, L. (2004). Mortality and morality: ageing and the ethics of care. *Ageing and Society*, 24, 235-256.

Lo, B., Saika, G. & Strull, W. (1985). Do not resuscitate decisions. A prospective study at three teaching hospitals. *Archives of Internal Medicine*, 145, 1115-17.

Lo, B. (1991). Unanswered questions about DNR orders. *Journal of the American Medical Association*, 265 (14), 1874-1875.

Lo, B. & Steinbrook, R. (2004). Resuscitating advance directives. *Archives of Internal Medicine*, 164 (14), 1501-1506.

Lofmark, R. & Nilstun, T. (1997). Do not resuscitate orders: Should the patients be informed? *Journal of Internal Medicine*, 241, 421-425.

Luttrell, S. & Summerville, A. (1996). Limiting risks of curtailing rights: a response to Dr. Ryan'. *Journal of Medical Ethics*, 27 (3), 274-277.

Madriz, E. (2000). Focus groups in feminist research. In Denzil, N.K. & Lincoln, Y.S. (eds.) *Handbook of qualitative research.* (pp. 835-850) Thousand Oaks, California: Sage.

Maddux, J.E. & Rogers, R.W. (1983). Protection motivation and self-efficacy: a revised theory of fear appeals and attitude change, *Journal of Experimental Social Psychology*, 19, 469-79.

Marik, P.E., Zaloga, G.P. (2001) CPR in terminally ill patients, *Resuscitation*, 49(1), 99-103.

Mark, D.F., Murray, M., Evans, B. & Willing, C. (2000). *Health Psychology: Theory, Research and Practice.* London: Sage.

Matheis-Kraft, C. & Roberto, K. (1997). Influences of a value discussion on congruence between elderly women and their families on critical heath care decisions. *Journal of Women & Ageing*, 9, 5-22.

Martin, L., L., & Clark, L., F., (1990). Social Cognition: Exploring the Mental Processes Involved in Human Social Interaction. In M. W. Eysenck (Ed.), *Cognitive Psychology: An International Review.* (pp. 266-310). Sussex: Wiley.

Matthews, E. (1996) Can paternalism be modernised? *Journal of Medical Ethics*, 12, 133-135.

McPherson, C.J. & Addington-Hall, J.M. (2003). Judging quality of care at the end of life: can proxies provide reliable information? *Social Science and Medicine*, 56, 95- 109.

Mead, G.E. & Turnbull, C.J. (1995). Cardiopulmonary resuscitation in the elderly: patients and relatives' views. *Journal of Medical Ethics*, 21, 39-44.

Miles, M.B. & Huberman, A.M. (1994). *An expanded sourcebook: Qualitative Data Analysis*. London: Sage.

Miles, S.H., Koepp, R. & Webb, E.P. (1996). Advance end-of-life treatment planning: A research review. *Archives in Internal Medicine*, 156, 1062-1068.

Miller, D.L., Jahnigen, D.W., Simbartl, L. (1992). Cardiopulmonary resuscitation: How useful? Attitudes and knowledge of an elderly population, *Archives of Internal Medicine*, 152, 578-82.

Molloy, D.W., Guyatt, G.H., Alemayehu, E. (1991). Treatment preferences, attitudes towards advance directives and concerns about healthcare. *Humane Medicine*, 7, 285-90.

Molloy, D.W., Stiller., A.K., Russo, R. (2000). Technology and educating seniors about advance directives, *Educational Gerontology*, 26, 357-369.

Morrison, R.S., Zayas, L. S., Mulvishill, M., Baskin, S.A., Meier, D.E. (1998). Barriers to completion of healthcare proxies: An examination of ethnic differences. *Archives of Internal Medicine*, 158, 2493-97

Morgon, D.L. (1988). *Focus groups as Qualitative Research.* Newbury Park: CA: Sage.

Morgan, R., King, D., Prajapati, C., Rowe, J. (1994). Views of elderly patients and their relatives on cardiopulmonary resuscitation. *British Medical Journal*, 308, 1677-8.

Murray, M. & Chamberlain, K. (1999). *Qualitative Health Psychology: Theories and methods*. London: Sage.

Murphy, D.J. Burrows, D., Santilli, S., Kemp, A.W. et al. (1994). The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. *New England Journal of Medicine*, 330, 545-549.

Norman, P. & Smith, L. (1995). The theory of planned behaviour and exercise: An investigation into the role of prior behaviour, behavioural intentions and attitude variability. *European Journal of Social Psychology*, 25, 403-415.

Norman, P; Conner, M; Bell, R. (2000). The theory of planned behaviour and exercise: Evidence for the moderating role of past behaviour. *British Journal of Health Psychology*, 5, 249-261.

Nisbett, R.E., & Wilson, T.D. (1977). Telling more than we know: Verbal reports on mental processes. *Psychological Review*, 84, 231-259.
Ogden, J. (2003). Some problems with social cognition models: A pragmatic and conceptual analysis. *Health Psychology, 22*, 424-428.

Ogden, J. (2004). Health Psychology: A textbook (3rd edition). Buckingham: Open University Press.

O'Keeffe, S.T., Noel, J., Lavan, J.N. (1993). Cardiopulmanary resuscitation preferences in the elderly. *European Journal of Medicine*, 2, 33-5.

O'Leary, A. (1992). Self-efficacy and health: Behavioural and stress-psychological mediation. *Cognitive therapy & Research*, 16, 229-245.

Oliver, R.L. & Berger, P.K (1979). A path analysis of preventive care decisions models, *Journal of Consumer Research*, 6, 113-22.

Orbell, S. & Sheeran, P. (1998). "Inclined abstainers": A problem for predicting health-related behaviour, *British Journal of Social Psychology*, 37, 151-165.

Ouellette, J.A. & Wood, W. (1998). Habit and intention in everyday life: The multiple processes by which past behaviour predicts future behaviour. *Psychological Bulletin*, 124, 54-74.

Owen, G.R. & Payne, S. (1999). Qualitative research in the field of death and dying. In M. Murray & K.Chamberlain (eds). *Qualitative Health Psychology: Theories and methods*. London: Sage. P. 148-163.

Oxford Concise Medical Dictionary (1998). Oxford: Oxford University Press.

Oxford Concise Medical Dictionary (1998). Oxford: Oxford University Press.

Palker, N.B., Nettles-Carson, B. (1995). The prevalence of advance directives: Lessons from a nursing home. *Nurse Practice*, 20(2), 7-8

Patel, R.V., Sinuff, T., Cook, D.J. (2004). Influencing advance directive completion rates in non-terminally ill patients: A systematic review, *Journal of Critical Care*, 19(1), 1-9.

Petty, R.E. & Krosnick, J.A. (1995). *Attitude strength: Antecedents and consequences*. Mahwah NJ: Erlbaum.

Phillips, R.S., Wenger, N.S., Teno, J., Oye, R.K. et al. (1996). Choices of seriously ill patients about cardiopulmonary resuscitation: Correlates and outcomes. *The American Journal of Medicine*, 100, 128-137.

Phillips, K. & Woodward, V. (1999). The decision to resuscitate: older people's views. *Journal of Clinical Nursing*, 8, 753-761.

Pope, C. & Mays, N. (1995). Qualitative research: Researching the parts other methods cannot reach: an introduction to qualitative methods in health and health service research. *British Medical Journal*, 311, 42-45.

Pratt, C.C., Jones, L.L., Hwa-Yong Shin, and Walker, A.J. (1989). Autonomy and Decision-Making Among Single Older Women and their Caregiving Daughters. *The Gerontologist,* 29, 792-97.

Phillips, R.S., Califf, R., Teno, J.M. (2000). Patients who want their family and physician to make resuscitation decisions for them: Observations from SUPPORT and HELP. *Journal of American Geriatrics Society*, 48, S84-S90.

Povey, R; Conner, M., Sparks, P., James, R., Shepard, R.(2000). Application of the theory of planned behaviour to two dietary behaviours: role of perceived control and self-efficacy, *British Journal of Health Psychology,* 5, 121-139.

Prochaska, J.O. & DiClemente, C.C. (1982). Transtheoretical therapy: towards a more integrative model of change, *Psychotherapy: Theory Research and Practice*, 19, 276-88.

Prochaska, J.O., DiClemente, C.C., Norcross, J.C. (1992). In search of how people change: Applications to addictive behaviours. *American Psychologist*, 47, 1102-1114.

Puchalski, C.M, Zhong, Z., Jacobs, M.M. (2000) Patients who want their family and physicians to make resuscitation decisions for them: observations from SUPPORT and HELP. Hospitalised Elderly Longitudinal Project. *Journal of the American Geriatric Society,* 48, 284-290

Quill, T.E. (2000). Perspectives on care at the close of life. Initiating end of life decisions with seriously ill patients: addressing the "elephant in the room". *Journal of American Medical Association,* 284, 2502-7.

Randall, D. & Gibson, A. (1991). Ethical decision making in the medical professional -an application of the theory of planned behaviour. *Journal of Business Ethics,* 10, 405-418.

Reilly, R. Teasdale, T.A., McCaullough, L.B. (1994). Projecting patient's preferences about living wills: An invalid strategy for management of dementia with life threatening illness. *Journal of American Geriatric Society*, 42, 997-1003.

Resuscitation Council, UK. (February 2000). CPR guidance for clinical practice and training in hospitals. http://www.resus.org.uk/.

Resnick, L., Cowart, M.E., Kubrin, A. (1998). Perceptions of do-not-resuscitate orders. *Social Work Health Care*, 26 (4), 1-21.

Rhodes, R. E., & Courneya, K. S. (2003). Relationships between personality, an extended theory of planned behaviour model and exercise behaviour. *British Journal of Health Psychology, 8,* 19-36

Richardson, L. (1994). Writing: A method of inquiry. In Handbook of Qualitative Research, Denzil, N. & Lincoln, Y. eds., Sage Publications. California, p. 516-529.

Rimal, R.N. (2000). Closing the knowledge-behaviour gap in health promotion: The mediating role of self-efficacy. *Health Communication*, 12, 219-237.

Rippetoe, P.A. & Rogers, R.W. (1987).Effects of components of protection motivation theory on adaptive and maladaptive coping with a health threat, *Journal of Personality & Social Psychology*, 52, 596-604.

Roberto, K.A., (1999). Making critical health care decisions for older adults: consensus among family members. *Family Relations*, *48*, 167-175.

Rogers, R.W. (1975). A protection motivation theory of fear appeals and attitude change. *Journal of Psychology*, 91, 93-114.

Roger, R.W. (1985). Attitude change and information integration in fear appeals. *Psychological Reports*, 56, 179-82.

Rosen, C.S. (2000). Integrating state and continuum models to explain processing of exercise messages and exercise initiation among sedentary college students. *Health Psychology*, 18, 272-280.

Rosenfeld, K., Wenger, N.S., Kagawa-Singer, M. (2000). End-of-life decision making: A qualitative study of elderly individuals. *Journal of General Internal Medicine*, 15, 620-625.

Rosenstock, I.M. (1966). Why people use health services. *Millbank Memorial Fund Quarterly*, 44, 94-124.

Rosenstock, I.M. (1990). The health belief model: Explaining health behaviour through expectancies. In K. Glanz, F.M. Lewis, B.K., Rimer (Eds.) *Health behaviours and health education: Theory, research and practice* (pp. 39-62). San Francisco: Joss-Bass.

Rutter, D. (2000). Attendance and re-attendance for breast cancer screening: A prospective 3 year test of the theory of planned behaviour. *British Journal of Health Psychology*, 5, 1-13.

Rutter, D. and Quine, L. (2002). *Changing Health Behaviour*. Buckingham: Open University Press.

Ryan, C.J. (1996). Betting your life: an argument against certain advance directives. *Journal of Medical Ethics*, 22, 95-99.

Sanderson H. (2004). Lessons from the central Hampshire electronic health record pilot project: evaluation of the electronic health record for supporting patient care and secondary analysis. *British Medical Journal,* 328, 875-78.

Sarantakos, S. (1998) *Social Research* (2nd ed). South Yarra: MacMillan Education Australia.

Saunders, C., & Baines, M. (1983). *Living with dying: the management of terminal disease.* Oxford: Oxford University Press.

Sayers, G.M., Schofield, I., Aziz, M. (1997). An analysis of CPR decision making by elderly patients. *Journal of Medical Ethics*, 23, 207-212.

Scanlon, C. (2003). Ethical concerns in end-of-life care: when questions about advance directives and the withdrawal of life-sustaining interventions arise, how should the decision be made? *American Journal of Nursing*, 103 (1), 48-55,

Schade, S.G. & Muslin, H. (1989). Do not resuscitate decisions: discussions with patients. *Journal of Medical Ethics*, 15, 186-190.

Schiff , R., Rajkumar, C., Bulpitt, C. (2000). Views of elderly people on living wills: Interview study. *BMJ,* 320, 1640-1.

Schneider, P.A., Nelson, D.J., & Brown, D.J. (1993). In hospital cardiopulmonary resuscitation: a 30 year review. Journal of the American Board of Family practice, 6, 91-101.

Schonertter, R.S., Walker, R.M., Kramer, D.R., Robinson, B.E. (1993). Resuscitation decision making in the elderly: the value of outcome data. *Journal of General Internal Medicine*, 8, 295-300.

Schonwetter, R.S., Walker, R.M., Kramer, D.R., & Robinson, B.E. (1994) Socioeconomic status and resuscitation preferences in the elderly, *Journal of Applied Gerontology,* 13 (2), 157-171.

Schwarzer, R. (1992). Self-efficacy in the adoption and maintenance of health behaviour: Theoretical approaches and a new model. In R. Schwarzer (eds.) *Self efficacy: Thoughts Control of Action,* pp. 217-43. Washington, D.C: Hemisphere.

Schwarzer, R., & Fuchs, R. (1995). Changing risk behaviors and adopting health behaviors: The role of self-efficacy beliefs. In A. Bandura (Ed.), *Self-efficacy in changing societies* (pp. 259-288). New York: Cambridge University Press.

Seale, C. (1991). Communication and awareness about death: A study of a random sample of dying people. *Social Science & Medicine*, 32 (8), 943-952.

Seale, C. (2000). Changing patters of death and dying. *Social Science & Medicine*, 51, 917-930.

Seal, C & Addington-Hall, J. (1995). Dying at the best time. *Social Science & Medicine*, 40 (5), 589-595.

Seale, C. & Cartwright, A. (1996). *The year before death* (2nd eds.) Hants: Avebury.

Seckler, A. Meier, D., Mulvihill, M. & Paris, B. (1991). Substituted judgement: How accurate are proxy predictions? *Annals of Internal Medicine*, 115 (2), 92-98.

Seymour, J. (2000). Negotiating natural death in intensive care. *Social Science & Medicine*, 51, 1241-1252.

Seymour, J., Bellamy, G., Gott, M., Ahmedzai, S. & Clark, D. (2002a). Using focus groups to explore older people's attitudes to end-of-life care, *Ageing and Society*, 22, 517-526.

Seymour, J.E., Clark, D., Gott M., Bellamy, G., & Ahmedzai, S. (2002b). Good deaths, bad deaths: Older people's assessments of risks and benefits in the use of morphine and terminal sedation in end of life care. *Health, Risk and Society*, 4 (3), 287-303.

Seymour, J., Gott, M., Bellamy, G., Ahmedzai, S., Clark, C. (2004) Planning for the end of life: the views of older people towards advance care statements. *Social Science & Medicine*, 59, 57-68.

Sehgal, A., Galraith, A. & Chesney, M. (1992). How strictly do dialyses patients want their advance directives followed? *Journal of American Medical Association*, 267, 59-63.

Sheeran, P. & Orbell, S. (1999). Implementation intentions and repeated behaviour: augmenting the predictive validity of the theory of planned behaviour, *European Journal of Social Psychology*, 29, 349-369.

Shepardson, L.B., Gordon, H.S., Ibrahim, S.A. Harper, D., Rosenthal, G.R. (1999). Racial variations in the use of do-not-resuscitate orders. *Journal of General Internal Medicine*, 14, 15-20.

Sheppard, B., Hartwick, J., Warshaw, P. (1988). The theory of reasoned action: a meta-analysis of past research with recommendations for modifications and future research. *Journal of consumer research*, 19, 105-118.

Silverira, M.J., DiPiero, A., Gerrity, M.S., Feudtner, C. (2000). Patients' knowledge of options at the end of life: Ignorance in the face of death. *American Medical Association*, 284 (19), 2483-2488.

Silvestri, G. (2003). Substituted judgement: the role of advance directive and durable power of attorney. International Consensus Conference in Intensive Care Medicine. End of life care in the ICU: Legal difference. Challenges in end-of-life care in the ICU, Brussels, 24th-25th April. Retrived on 15th of January 2005 from http://www.esicm.org/consensus/Silvestrin%20text.htm

Singer, P.A., Martin, D.K., Lavery, J.V., Theil, E.C., Kelner, M. & Mendelsoonhn, D.C. (1998). Reconceptualising advance care planning from the patients' perspective. *Archives of Internal Medicine*, 158, 879-884.

Singer, P.A., Martin, D.K. Kelner, M. (1999). Quality End-of-Life Care: Patients' Perspectives. *Journal of American Medical Association*, 281, 163-168.

Smith, J.K. (1990). Alternative research paradigms and the problem of criteria. In E.G. Guba (Ed.), *The Paradigm Dialog*, London: Sage.

Smith, J.A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in Health Psychology, *Psychology and Health*, 11, 261-71.

Smith, J.A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K.Chamberlain (eds). Qualitative Health Psychology: Theories and methods. London: Sage.

Smith, J.A. (2004). Interpretative phenomenological analysis. In J. Smith (ed.). *Qualitative Psychology: A practical guide.* London: Sage

Smith, R. (2000). A good death: An important aim for health services and for us all. *BMJ*, 320, 129-130. http://www.bmj.com; accessed on 29/01/01.

Spark, P. (1994). Food choice and health: applying, assessing and extending the theory of panned behaviour. In D.R. Rutter & L. Quinne (eds.). *Social Psychology and Health: European Perspectives*, pp25-46. Aldershot: Averbury.

Sparks, P., Shepherd, R., Wieringa, N. & Zimmermanns, N. (1995). Perceived behavioural control, unrealistic optimism and dietary change: An exploratory study. *Appetite*, 24, 243-255.

Sparks, P. Guthrie, C.A. & Shepherd, R. (1997).The multi-dimensional structure of the "perceived behavioural control" construct. *Journal of Applied Social Psychology*, 27, 418-438.

Sparks, P., Conner, M., James, R., Shepherd, R., Povey, R. (2001). Ambivalence about health related behaviours: An exploration in the domain of food choice. *British Journal of Health Psychology*, 6, 53-68.

Stainton Rogers, W. (1991). *Explaining health and illness: An exploration of diversity*. London: Harvester Wheatsheaf.

Stein, H. (1989). Family influences on heath behaviour: An ethnographic approach. In C. Ramsey (Ed.). *Family systems in medicine*, pp 373-393. New York: The Guildford Press.

Steinberg, M, Youngner, S. (1998) *End of life Decisions: A Psycho-social Perspective.* Washington, DC: American Psychiatric Press, 109-136

Steward, K., Wagg, A., Kiniros, M. (1996). When can elderly patients be excluded from discussing resuscitation. *Journal of Royal College of Physicians London*, 30, 133-5.

Stewart K., Spice, C., Rai, G. (2003). Where now with the do not attempt resuscitation decisions? *Age & Ageing*, 32, 143-148.

Stiles, W. (1993). Quality control in Qualitative research, *Clinical Psychology Review*, 13, 593-618.

Stoddard, J. (1998). A practical approach to DNAR discussion, *Bioethics Forum*, 14 (1), 27-33.

Sudnow, D. (1967). *Passing on: The social organisation of dying*. Englewood Cliffs: New York: Prentice Hall.

Suhl, J., Simons, P., Reddy, T. & Garrick, T. (1994). Myth of substituted judgement: Surrogate decision making regarding life support is unreliable. *Archives of Internal Medicine*, 154, 90-96.

Sulmasy, D.P., Terry, P.B., Weisman, C.S. (1998). The Accuracy of Substituted Judgments in Patients with Terminal Diagnoses, *Annals of Internal Medicine*, 128 (8), 621-629

SUPPORT Principal Investigators for the SUPPORT Project (1995). A controlled trail for seriously hospitalized patients: The study to Understand Prognosis and Preferences for Outcome and Risks of Treatments (SUPPORT). *Journal of American Medical Association*, 274, 1591-8.

Sutton, S., Bickler, G., Sancho-Aldridge, A., & Saidi, G. (1994). Prospective study of predictors of attendance for breast screening in inner London. *Journal of Epidemiology and Community Health,* 48, 65-73.

Sutton, S. (1998). Predicting and explaining intentions and behaviour. How well are we doing? *Journal of Applied Social Psychology,* 28, 1317-1338.

Tabachnick, B.G. & Fidel, L.S. (1996). *Using multivariate statistics.* New York: Harper Collins

Taylor, E.M., Parker, S. & Ramsey, M.P. (1998). Patients' receipt and understanding of written information about a resuscitation policy. *Bioethics,* 12 (1), 65-76.

Templer, D.I. (1970) The construction and validation of a death anxiety scale. *Journal of General Psychology,* 82, 165-177.

Teno, J.M., Maruerite, D., Spernak, S., Lynn, J. (1998). Insights from qualitative and quantitative data. *Journal of General Internal Medicine,* 13, 439-446.

Terry, D.J. (1993). Self-efficacy experiences and the theory of reasoned action. In D.J. Terry, C. Gallois, & M. McCamish (Eds.). *The theory of reasoned action: Its application to AIDs-preventive behaviour* (pp.135-151). Oxford: Pergamon.

Thorns, A. (2000). Resuscitation in palliative care (editorial). *International Journal of Palliative Nursing,* 6, 264.

Timmermans, S.(1999). *Sudden death and the myth of CPR.* Philadelphia: Temple University Press.

Todd, Z., Nerlick, B., McKeown, S. & Clarke, D.D. (2004). *Mixing methods in Psychology: The integration of qualitative and quantitative methods in theory and practice.* Psychology Press: Hove.

Tomer, A.T. (2000). *Death attitudes and the older adult: Theories, concepts and application.* Ann Harbour: Taylor and Francis.

Trafimow, D., Sheeran, P., Conner, M. and Finlay, K. A. (2002) Evidence that perceived behavioral control is a multidimensional construct: Perceived control and perceived difficulty. *British Journal of Social Psychology,* 41: 101-122.

Triandis, H. (1977). *Interpersonal behaviour.* Monterey, CA: Brooks/Cole.

The SUPPORT Investigators. (1995). A control trail to improve care for seriously ill hospitalised patients. *Journal of the American Medical Association,* 274, 1591-1598.

Tustall-Pedoe, H (1992). Survey of 3765 cardiopulmanary resuscitations in British Hospitals (the BRESUS Study): method and overall results. *British Medical Journal*, 304, 1347-1351.

Uhlmann, R.F., Pearlman, R.A., & Cain, K.C. (1988). Physicians' and their spouses' predictions of elderly patients' resuscitation preferences. *Journal of Gerontology*, 43, M115-M121.

Ussher, J.M. (1994). Sexing the phalocentric pages of psychology – repopulating is not enough. *Theory and Psychology*, 4 (3), 345-352.

Vaughn, G., Kiyasu, E., McComick, W.C. (2000). Advance directive preferences among subpopulations of Asian nursing home residence in the Pacific Northwest. *Journal of American Geriatrics Society*, 48, 554-557.

Verbrugge, L.M. (1989). The twain meet: Empirical explanations of sex differences in health and mortality. *Journal of Health and Social Behaviour*, 30, 282-307.

de Vos, R., Koster, R.W., de Haan, R.J. (1998). Impact of survival probability, life expectancy, quality of life and patient preferences on do-not-attempt-resuscitation orders in a hospital. *Resuscitation,* 39, 15-21.

Victor, C.R.(1993). Health policy and services for dying people and their carers. In D. Dickenson and M. Johnson (eds.), *Death, Dying and Bereavement*. London: Sage.

Volicer, L., Cantor, M.D., Derse, A.R., Edwards, D.M. et al. (2002). Advance care planning by proxy for residence of long-term facilities who lack decision-making capacity. *Journal of American Geriatrics Society*, 50, 761-762.

Von Gunten, C.F. (1991). CPR in hospitalised patients: when is it futile? *American Family Physician*, 44, 2130-2134.

Watcher, R.M., Luce, J.M., Hearst, N., Lo, B. (1989). Decisions about resuscitation: inequities among patients with different diseases but similar prognoses. *Annals of Internal Medicine*, 111, 525–532.

Watson, D.R., Wilkinson, T.J., Sainsbury, R., Kidd, J.E. (1997). The effect of hospital admission on the options and knowledge of elderly patients regarding cardiopulmonary resuscitation. *Age Ageing*, 26, 429-34.

Waters, C.M. (2000). End of life care directives among African American: Lessons learnt – A need for community-centred discussion and education. *Journal of Community Health Nursing*, 7 (1), 25-37.

Weber, R.P. (1990). *Basic content analysis.* London: Sage. 2^{nd} edition.

Weiner, B. (1980). *Human Motivation.* NY: Holt, Rinehart & Winston.

Weiss, G.B. (1985). Paternalism modernised. *Journal of Medical Ethics,* 1, 133-135.

Weiss, G.L. & Hite, C.A. (2000). The do-not-resuscitate decision: The context, process, and consequences of DNR order. *Death Studies,* 24, 307-323.

Weissman, J.S., Hass, J.S., Fowler, F.J., Gatsonis, C., Massagli, M.P., Seage, G.R. & Clery, P. (1999). The stability of preferences for life sustaining care among persons with AIDS in the Boston Health study. *Medical Decision Making,* 19, 16-26.

Wenger, N.S., Kanouse, D.E., Collins, R.L., Liu, H., Schuster, M.A., Gifford, A.L., Bozzetter, S.A., Shapiro, M.F. (1995). End-of-life discussions and preferences among persons with HIV. *Journal of American Medical Association,* 285 (22), 2880-2887.

Wenger, C.G. & Jerrome, D. (1999). Change and stability in confidant relationships: Findings from the Bangor Longitudinal Study of Ageing. *Journal of Ageing Studies,* 13 (3), 269-294.

Weisman, C. (1974). *The realisation of death.* New York: Jason Aronson.

Weinstein, W.D. (1988). The precaution adoption process. *Health Psychology,* 7, 355-86.

Wilkinson, S. & Kitzinger, C. (1996). *Representing the other: A feminism and psychology reader.* London: Sage

Williams, R. (1990). *A Protestant Legacy: Attitudes to death and illness among younger Abergonians.* Oxford: Clarendon Press

Williams, R. (1993). The 'do not resuscitate' decision: guidelines for policy in the adult. *Journal of Royal College of Physicians,* 27, 139-140.

Willig, C. (2002). *Introducing qualitative research in Psychology: Adventures in theory and method.* Buckingham: Open University Press.

Wilson, D.M. (1999). End-of-life care preferences of Canadian senior citizens with caregiving experience. *Journal of Advanced Nursing,* 31 (6), 1416-1421.

Wong, P. T. P. (1989). Successful aging and personal meaning. *Canadian Psychology*, 30, 516-525.

Yardley, L. (1999). Understanding embodied experience: Beyond mind- body dualism in health research. In M. Murray & K. Chamberlain (eds). *Qualitative Health Psychology: Theories and methods*. London: Sage. P. 30-46.

APPENDIX 1: INFORMATION SHEET FOR STUDY 1

What is the study about and who are we?

This study is investigating older people's views about their medical decision-making during the later stages of life. This is becoming an important topic, since medical advances can now keep people physically alive, sometimes without talking with the patient about their preferences. The aim of our study is to find out how we can help people have good discussions with their doctors, nurses and family members about these difficult issues.

This study is part of a research project being conducted in the University of Surrey under the direction of Professor Sarah Hampson (a health psychologist). My name is Tushna Vandrevala and I am working directly with the people who participate in the study.

What will you be asked to do?

We will ask interview you about your views on end-of-life care; more specifically your views on life prolongation. The interview should only take 40-45 minutes to complete. There are no right or wrong answers to the questions. We are interested in what you have to say. You can choose not to answer any questions that you would rather not. You will be asked to sign a consent form. The interview will be audiotaped and transcribed so that we are able to analyse the results.

Benefits and Risks

No one particularly likes to think or talk about the end-of-life issues and dying. We appreciate this, and therefore value your participation even more because we believe that there are great benefits of a study such as ours for improving health care for people at the end of their lives. This study will help us to find ways to improve communication between patients, doctors and family members about these difficult topics. As a result, patients' wishes are more likely to be heard and acted upon.

All the information you provide will be completely anonymous and confidential. Nothing we report could be traced back to you.

We have provide you with names and contact details of organisations that might be helpful to you if you decide you would like to find out more about end-of-life care.

How to reach us?

For further information about the project, please feel free to contact me Tushna on 01483 682886 or on t.vandrevala@surrey.ac.uk

APPENDIX 2: CONSENT FORM FOR STUDY 1

UniS

University of Surrey
Department of Psychology

I, the undersigned voluntarily agree to take part in this study.
I have read and understood the information sheet provided. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given.

I understand that all personal data from this study will be stored and handled with the strictest confidence and anonymity, in accordance with the Data Protection Act (1998).

I understand that I am free to withdraw from the study at any time without reason and needing to justify my decision.

I confirm that I have read and understood the above and freely consent to participate in the study.

Name of volunteer ....
Signed ....
Date ....
Address ....
....
Telephone Number ....

Name of witness ....

Signed ....

Would you like to be contacted for further studies, on this topic?

Yes, I would like to be contacted   No, I do not wish to be contacted.

APPENDIX 3: INTERVIEW SCHEDULE FOR STUDY 1

1). To what extent are you interested in cases like the recent one of Diane Pretty?

If participants had not heard about the case, they were given a brief description –

Diane Pretty case was a high profile case on 'dying with dignity' at the time the interviews were conducted. The 43-year-old mother of two was a sufferer of motor neurone disease and had decided that she did not want life prolongation by artificial means by ventilation or tube feeding. She was also in a case trying to win in favour of assisted suicide.

Prompt participants to talk about related issues about death and dying.

2). In this study we will be addressing issues regarding resuscitation and advance care planning. Have you ever thought about these issues? How much do you know about this?

Explanation of CPR and DNAR provided to participants is needed.

What values would be important to a person when talking or making decisions about end-of-life care?

If participants was willing, they were encourages to talk about themselves and their thoughts about these issues.

3). How important is it for older people to be involved in your own medical decisions?

4). To what extent should the family normally be involved in an older persons' medical care?

5). To what extent should medical professionals normally be involved in an older persons' medical care?

6). How easy would it be for you to talk about medical care in your final stages of life?

With your doctor? With your family members?

7). Do you have any views about "living wills" or "advance directives"?

If required an explanation was provided.

In what situation would you consider signing one?

What are the pros and cons of signing one?

8) What are your thoughts and feeling about discussing these issues with the interviewer? Did you find the subject distressing or stressful?

Thank you for your time and help.

APPENDIX 4: ORGANISATIONS THAT CAN HELP

Organisations that can help

Age Concern England
1268 London Road
London SW1 64 ER
Help and Advice Line: 0800 8086060
Website: www.ageconcern.org.uk

Help the Aged
Clerkenwell Green
London SW4 1SZ
Help and Advice Line: 0800 8006565

Discussing difficult and sensitive issues

Cruse Bereavement Care:
Offers free and confidential counselling serice and support to those bereaved by death
Tel: 0208 9404818

Information on resuscitation and living wills

Medical Ethics Society, British Medical Association
Tavistock Square
London WC1H 9JP
Tel: 02027 3836286
Website: www. bma.org.uk

Resusciation Council, UK
5th floor, Tavistock Square
London WC1H 9JP
Tel: 02073884678
Website: www.resus.org.uk

Voluntary Euthanasia Society
13, Prince of Wales Terrace
London W8 5PG
Tel: 0207 9377770
Website: www.ves.org.uk

Natural Death Centre
20, Heber Road
London NW2 6AA
Tel: 0208 2082853

APPENDIX 5: ADVERT FOR STUDY 2

UniS
University of Surrey
Department of Psychology

Personal Autonomy & Medical Decision-Making

At the Department of Psychology, University of Surrey we are conducting research into medical care in the final stages of life and the degree to which older people would like to participate in the decision making process.

Participants will be asked to complete a questionnaire on living wills, life-prolongation measures, such as resuscitation and the degree to which they would like to discuss these issues with doctors and family members.

Volunteers should be aged 60 or over. Anyone interested in finding out more about the study should contact:

Tushna Vandrevala
Department of Psychology
University of Surrey
Guildford
GU2 7XH
Tel. 01483-682886

t.vandrevala@surrey.ac.uk

This project is approved by the University of Surrey Advisory Committee on Ethics.

APPENDIX 6: INFORMATION SHEET FOR STUDY 2 (TIME 1)

Personal Autonomy & Medical Decision-Making

What is the study about and who are we?

This study is investigating older people's views about their medical care during the final stages of life. This is becoming an important topic, since medical advances can now keep people physically alive, sometimes without talking with the patient about their preferences. We are particularly interested in studying older people, who are not in hospital, because this is a good time for people to think about and make decisions about the kind of care they would like to receive. The aim of our study is to find out how we can help people have good discussions with their doctors, nurses and family members about these difficult issues.

This study is part of a research project being conducted in the University of Surrey under the direction of Professor Sarah Hampson (a health psychologist) and Professor Hilary Thomas (an oncologist). My name is Tushna Vandrevala and I will be working directly with the people who participate in the study.

What will you be asked to do?

You will be given/sent a questionnaire to complete at home at your own pace. It will take about 20 minutes to complete, although some people are faster than others. There are no right or wrong answers to the questions. We are interested in what you have to say. The questions find out how much you know about options for medical care at end of life, and how you feel about the idea of discussing end-of-life care with your doctors, nurses, and family members. There are some questions that ask you about how you feel about death and dying. You can choose not to answer any questions that you would rather not. You will be asked to post the completed questionnaire back to me, at no expense to you.

Benefits and Risks

No one particularly likes to think or talk about the end-of-life issues and death. We appreciate this, and therefore value your participation even more because we believe that there are great benefits of a study such as ours for improving health care for people at the end of their lives. This study will help us to find ways to improve communication between patients, doctors and nurses about these difficult topics. As a result, patients' wishes are more likely to be heard and acted upon.

We appreciate that answering some of the questions could be upsetting and distressing for you. You are under no pressure to participate, and if you feel that it would be upsetting for you, then you should not. If you do decide to participate, you can choose only to answer those questions that you feel comfortable answering, skipping any that you find upsetting or distressing.

All the information you provide will be completely anonymous. We will never present an individual's answers so nothing we report could be traced back to you. We will provide you with names and contact details of organisations that might be helpful to you if you decide you would like to find out more about end-of-life care.

How to contact us?

For further information about the project please feel free to contact me Tushna Vandrevala at the Department of Psychology, University of Surrey, Guildford, Surrey GU2 7XH or on 01483-682886 or by email at t.vandrevala@surrey.ac.uk

Please feel free to take time to think about whether or not to participate in the study, or to discuss it with someone before deciding.

APPENDIX 7: TIME 1 QUESTIONNAIRE

ID no ☐

Please circle the answer that best describes you.

Section 1: Background Information

1. **Age** under 60 60-69 70-79 80-89 90-100

2. **Gender**

Male Female

3. **Religion**

Christianity (indicate which church you belong to)__________

Hinduism Islam Jewish Buddhism

Others________ None

4. **Ethnicity**

White South-Asian South-east Asian African

Other

5. **In which country were you born?** __________

6. **Who do you live with ?**

Alone Family Friends Institutional setting

7. **What is your level of education?**

Less than secondary school Secondary school

College/Post-secondary University/Graduate Post Graduate

8. **Present marital status**

Single Married Widowed Divorced

9. **Approximate annual income**

Up to £5,000 £5,000-£10,000 £10,000-£20,000

£20,000-£30,000 £30,00-£40,000 £40,000-£50,000 Over £50,000

10. **Occupation Status**

Employer Employee Retired Self Employed Other

11. **Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?**

Yes No

12. **Have you been admitted into hospital in the past 5 years?**

Yes No

13. **Indicate for what purpose you were admitted**____________

Section 2: Your Views on End-of-Life Issues

14. I am comfortable talking about death and dying

Strongly agree Agree Disagree Strongly disagree

15. I am comfortable talking about end-of-life care, such as resuscitation, and advance care planning.

Strongly agree Agree Disagree Strongly disagree

16. Who would you be most likely to discuss end-of-life issues with? (rank order from 1 to 8, using 1 for the most likely person and 8 for the least likely)

Spouse Religious Head/Clergy
Children Nurse
Siblings Other medical professionals
Friends GP

17. Who would you most like involved in decision-making about your end-of-life care ? (rank order from 1 to 8, using 1 for the person you would most like, and 8 for the person you would least like)

Spouse Religious Head/Clergy Children Nurse
Siblings Other medical professionals Friends GP

In the following questions (18-23), indicate (by circling) your feelings about the following statement

I think that taking about end-of-life issues with my doctor would be

18. Very Good	Good	Bad	Very Bad
19. Very Helpful	Helpful	Unhelpful	Very Unhelpful
20. Very Negative	Negative	Positive	Very Positive
21. Very harmful	Harmful	Beneficial	Very Beneficial
22. Very satisfying	Satisfying	Unsatisfying	Very Unsatisfying
23. Very useful	Useful	Unless	Very Unless

Section 3: Your Beliefs About Medical Professionals

24. I trust doctors to make the right decision about my medical care, if I were to be very ill or in a coma

Strongly agree Agree Disagree Strongly disagree

25. I worry that I won't be treated as well as other people in the hospital if I were to be very ill or in coma

Strongly agree Agree Disagree Strongly disagree

26. I worry that I won't be treated as well as other people in the hospital because I am old

Strongly agree Agree Disagree Strongly disagree

27. I believe that the medical professionals are solely responsible for making my end-of-life decision for me

Strongly agree Agree Disagree Strongly disagree

28. I want to talk to my doctor about the options for end-of-life care

Strongly agree Agree Disagree Strongly disagree

29. I would prefer my doctor to initiate these discussions

Strongly agree Agree Disagree Strongly disagree

30. I am uncomfortable talking to my doctor about end-of-life care

Strongly agree Agree Disagree Strongly disagree

31. I would only want to talk to my doctor about end-of-life care if I was terminally ill

Strongly agree Agree Disagree Strongly disagree

32. I would not want to talk to my doctor about end-of-life care if I was under the age of 60.

Strongly agree Agree Disagree Strongly disagree

33. I find discussion of end-of-life issues with my doctor irrelevant at this point to my life

Strongly agree Agree Disagree Strongly disagree

34. I feel the need to talk to my doctor about end-of-life issues.

Strongly agree Agree Disagree Strongly disagree

35. I have initiated these conversations with my doctor

Yes No

If Yes,

36. I was satisfied with this conversation.

Strongly agree Agree Disagree Strongly disagree

Section 4: Beliefs about Family Members' Involvement

37. I trust my family members to make the right decision about my medical care if I were to be very ill or in a coma

Strongly agree Agree Disagree Strongly disagree

38. I want my family members to be involved in my end-of-life decisions.

Strongly agree Agree Disagree Strongly disagree

39. I am comfortable with my family members making this decision for me

Strongly agree Agree Disagree Strongly disagree

40. My family will always make sure that I am treated right by the doctors

Strongly agree Agree Disagree Strongly disagree

41. I want to talk to my family about the options for end-of-life care

Strongly agree Agree Disagree Strongly disagree

42. I would prefer my family to be present, when my doctor to initiate these discussions

Strongly agree Agree Disagree Strongly disagree

43. I am uncomfortable talking to my family about end-of-life care

Strongly agree Agree Disagree Strongly disagree

44. I would only want to talk to my family about end-of-life care if I was terminally ill

Strongly agree Agree Disagree Strongly disagree

45. I would not want to talk to my family about end-of-life care if I was under the age of 65.

Strongly agree Agree Disagree Strongly disagree

46. I am comfortable asking one of my family members or close friends to make medical decisions for me, if I cannot make them for myself

Strongly agree Agree Disagree Strongly disagree

47. I find discussion of end-of-life issues with my family irrelevant at this point to my life

Strongly agree Agree Disagree Strongly disagree

48. I feel the need to talk to my family about end-of-life issues

Strongly agree Agree Disagree Strongly disagree

49. I have initiated these conversations with my family.

Yes No

If Yes,

50. I was satisfied with the discussion

Strongly agree Agree Disagree Strongly disagree

Section 5: Values Important to You When Making End-of-Life Decisions

51. I want to be treated with dignity when I can no longer speak for myself

Strongly agree Agree Disagree Strongly disagree

52. I do not want to be a burden on my family

Strongly agree Agree Disagree Strongly disagree

53. I want to experience a comfortable dying process

Strongly agree Agree Disagree Strongly disagree

54. I want to be able to make my own decision regarding my death

Strongly agree Agree Disagree Strongly disagree

55. I want to be treated in accordance with my religious beliefs

Strongly agree Agree Disagree Strongly disagree

56. I intend to talk about end-of-life issues with my GP in the next 6 months

Strongly agree Agree Disagree Strongly disagree

57. My family think I should discuss end-of-life issues with my GP

Strongly agree Agree Disagree Strongly disagree

58. If I wanted to discuss end-of-life issues with my GP I could do so

Strongly agree Agree Disagree Strongly disagree

59. It will be difficult for me to discuss end-of-life issues with my GP

Strongly agree Agree Disagree Strongly disagree

60. I plan to discuss end-of-life issues with my GP

Strongly agree Agree Disagree Strongly disagree

61. Have you made any plans as to when, where and with whom you intend to discuss end-of-life issues?

Yes No

If yes, Indicate

62. With whom you intend to have this discussion

63. When you intend to have this discussion

64. Where you intend to have this discussion

Section 6: Advance Directives

The terms 'advance directives', 'living wills' & 'advance statements' refer to same concept and hence will be referred to as 'living wills' in this questionnaire.

65. Have you heard of the term living wills?

Yes No

If the answer to the previous question was 'No', proceed to Section 6.

66. If so, what do you understand by the term living wills?.

67. Do you have an living will?

Yes No

If yes, proceed. If no, go to question no

68. Is your GP aware of that you have a living will?

Yes No

69. Did someone help you write your Living will? If so, indicate who below (e.g., relative, friend, lawyer)

70. Where do you keep your living will?

If you do not have an advanced directive,

71. Are you interested in signing an advance directive?

Yes No

72. I intend to sign an advance directive in the next 6 months

Strongly agree Agree Disagree Strongly disagree

73. My family think I should sign an advance directive/living will

Strongly agree Agree Disagree Strongly disagree

74. My GP would think that I should sign an advance directive

Strongly agree Agree Disagree Strongly disagree

75. If I wanted to write an advance directive tomorrow, I could do

Strongly agree Agree Disagree Strongly disagree

76. It will be difficult for me to sign an advance directive

Strongly agree Agree Disagree Strongly disagree

77. I always do what my family tells me to do

Strongly agree Agree Disagree Strongly disagree

78. I always do what my GP tells me to do

Strongly agree Agree Disagree Strongly disagree

Section 6:CPR

On admission to hospital, a full medical assessment of each patient is made. Doctors decide which treatment is appropriate for each patient. Doctors also decide whether or not to *resuscitate* a patient if he or she has a *cardiac arrest*. The medical practitioner is meant to discuss this with you before reaching a decision about resuscitation.

'Cardiac arrest' means that a patient's heart and lungs suddenly stop working and the patient collapses and becomes unconscious. **'Resuscitation'** involves doctors and patients pumping on a patient's chest (known as **CPR: Cardiopulmonary Resuscitation**), putting him or her on a drip, and if necessarily on a breathing machine. A small electric shock applied across the heart and lungs may also be needed. The aim is to restart the heart and lungs and revive the patient. Doctors can also make decisions *not to resuscitate* a patient, by putting a **DNAR (Do-Not-Attempt to Resuscitate)** on the patient's files. This ensures that resuscitation will not be initiated.

The purpose of this section is to find out how you feel about the resuscitation procedure.

79. Had you heard of CPR (Cardiopulmonary Resuscitation) before reading the previous paragraph?

Yes No

If Yes,

80. Where did you first hear about the CPR (Cardiopulmonary Resuscitation)?

Your GP, In the hospital, Television, Radio,
Books/Magazines, Family member Lawyer Others

81. Had you heard about the DNAR (Do-not-attempt to resuscitate) policy prior to it being mentioned here?

Yes No Don't Know

82. Have you been resuscitated?

Yes No

83. Has your doctor ever spoken to you about the DNAR policy and discussed CPR with you?

Yes No

84. Given a choice would like your life prolonged by CPR in the event of a cardiac arrest?

Yes No Not sure

85. How successful do you think CPR is? ("Success" means that a person's heart and lungs start working independently again. 10% means that 10 people in 100, 90% means 90 people in 100).

<10% 10-20% 20-30% 30--50% 50-70%

70-80% 80-90% 90%>

Section 7: Feelings about Death

82	**I am very much afraid to die**	Yes	No
83	**The thought of death seldom enters my mind**	Yes	No
84	**It does make me nervous when people talk about death**	Yes	No
85	**I dread to think about having to have an operation**	Yes	No
86	**I am not at all afraid to die**	Yes	No
87	**I am not particularly afraid of getting cancer**	Yes	No
88	**The thought of death never bothers me**	Yes	No
89	**I am often distressed by the way time flies so very rapidly**	Yes	No
90	**I fear dying a painful death**	Yes	No
91	**The subject of life after death troubles me greatly**	Yes	No

92	**I am really scared of having a heart attack**	Yes	No
93	**I often think about how short life really is**	Yes	No
94	**I shudder to think of people talking about World War III**	Yes	No
95	**The sight of a dead body is horrifying to me**	Yes	No
96	**I feel that the future holds nothing for me to fear**	Yes	No

97. My death does not end my personal existence

Strongly agree Agree Disagree Strongly disagree

98. Death is a transition to something even greater than this life

Strongly agree Agree Disagree Strongly disagree

99. I believe in life after death

Strongly agree Agree Disagree Strongly disagree

100. Death is never just an ending, but it is part of a process

Strongly agree Agree Disagree Strongly disagree

101. There is a Force or Power that controls and gives meaning to both life and death

Strongly agree Agree Disagree Strongly disagree

Section 8: Religion/Spirituality

102. How often do you attend church or other religious meetings?

More than once a week Once a week A few times a month A few time a year Once a year or less Never

103. How often do you spend time in private religious/spiritual activities, such as prayer, meditation, or bible studies.

More than one's a week Once a week A few times a month

A few time a year Once a year or less Never

104. In my life, I experience the presence of the Divine (i.e., God)

Definitely true of me Tends to be true Unsure

Tends *not* to be true Definitely *not* true

105. My religious/spiritual beliefs are what really lies behind my whole approach to life

Definitely true of me Tends to be true Unsure

Tends *not* to be true Definitely *not* true

106. I try hard to carry my religion/spirituality into all other dealings in life.

Definitely true of me Tends to be true Unsure

Tends *not* to be true Definitely *not* true

107. Religious/spiritual beliefs are important to me when making end-of-decisions

Strongly agree Agree Disagree Strongly disagree

Thank you once again for your participation

in the study

APPENDIX 8: LETTER SENT SIX MONTHS LATER

University of Surrey
Department of Psychology

Tushna Vandrevala
Guildford
Surrey GU2 7XH UK
Tel: *+44 (0)1483 682886*
Email: t.vandrevala@*surrey.ac.uk*

UniS

23rd October 2002

Personal Autonomy & Medical Decision-Making

You may remember that about six months ago you very kindly completed a questionnaire for me on 'medical decision-making in the later stages of life'. This was very helpful. I am now contacting you again to ask you for your help in completing a short questionnaire on the same issues. The questionnaire is a follow-up to the previous questionnaire and very important for the study. The questionnaire is enclosed.

Please remember that you can leave out any questions that you do not wish to answer and there are no right or wrong answers, it is your opinion that counts. All the information you provide will be kept anonymous and confidential. The questionnaire should only take 10-12 minutes to complete. Please post it back to me in the FREEPOST envelope provided.

Contact me on 01483 682886 or on t.vandrevala@surrey.ac.uk if you have any questions or concerns. I have also enclosed a list of organisations that may be helpful for you if this questionnaire raises any further issues for you.

Thank you very much for your help and participation in the study. Your help is greatly appreciated

Yours sincerely,

Tushna Vandrevala.

APPENDIX 9: INFORMATION SHEET AT TIME 2

Personal Autonomy & Medical Decision-Making

What is the study about and who are we?

As you probably remember, this study is investigating older people's views about their medical decision-making during the later stages of life. This is becoming an important topic, since medical advances can now keep people physically alive, sometimes without talking with the patient about their preferences. The aim of our study is to find out how we can help people have good discussions with their doctors, nurses and family members about these difficult issues.

This study is part of a research project being conducted in the University of Surrey under the direction of Professor Sarah Hampson (a health psychologist) and Professor Hilary Thomas (an oncologist). My name is Tushna Vandrevala and I am working directly with the people who participate in the study.

What will you be asked to do?

This is a follow up to the previous questionnaire you filled out 6 months go. The questionnaire should only take 10 minutes to complete. There are no right or wrong answers to the questions. We are interested in what you have to say. You can choose not to answer any questions that you would rather not. When you have finished, you post the completed questionnaire back at no expense to you. By completing the questionnaire, you are giving your informed consent.

Benefits and Risks

No one particularly likes to think or talk about the end-of-life issues and dying. We appreciate this, and therefore value your participation even more because we believe that there are great benefits of a study such as ours for improving health care for people at the end of their lives. This study will help us to find ways to improve communication between patients, doctors and family members about these difficult topics. As a result, patients' wishes are more likely to be heard and acted upon.

All the information you provide will be completely anonymous and confidential. We will never present an individual's answers so nothing we report could be traced back to you. We have provide you with names and contact details of organisations that might be helpful to you if you decide you would like to find out more about end-of-life care.

How to reach us?

For further information about the project, please feel free to contact me Tushna on 01483 682886 or on t.vandrevala@surrey.ac.uk

APPENDIX 10: TIME 2 QUESTIONNAIRE

Section 1: Discussing end-of-life issues with your doctor

ID

1.	In the past six months I have spoken to my doctor about end of life issues.	YES	NO
2.	Have you ever spoken to your doctor about end-of-life issues before?	YES	NO

If 'YES' to Q.1 or Q.2, then proceed. If 'NO' then go to Q 14. on pg. 2

3.	Circle which of the following end-of-life issues you discussed with your doctor in the past 6 months. (Circle all that apply)	Living wills Do-not-attempt to resuscitate order (DNAR) Ventilator withdrawal	Cardiopulmonary Resuscitation (CPR) Death & Dying Nutrition/ Hydration
4.	Who else was present at the discussion?	Family Friends Lawyer Nobody	Clergy/ Religious guide Other medical professionals (e.g. nurse) Others ____________

	The following questions are about the discussion you had with your doctor.	Strongly agree	Agree	Disagree	Strongly Disagree
5.	The presence of other medical professionals helped me talk about these issues. (if relevant)	1	2	3	4
6.	The presence of my family members helped me talk about these issues. (if relevant)	1	2	3	4
7.	I was satisfied with this conversation.	1	2	3	4
8.	Talking to my doctor about end-of-life issues was easy.	1	2	3	4
9.	I chose to discuss these issues with my doctor.	1	2	3	4

10	It was difficult to discuss these issues with my doctor.	1	2	3	4
11	My family thinks that I should discuss end-of-life issues with my doctor.	1	2	3	4
12	I am content with the conversation I had with my doctor.	1	2	3	4
13	What was the most important factor that made you decide to speak to your doctor about end of life issues?				

If 'NO' to Q. 1 OR Q.2 then answer the following questions. If you had answered 'YES' proceed to the next section.

		Strongly agree	Agree	Disagree	Strongly Disagree
14	I plan to discuss end-of-life issues with my doctor.	1	2	3	4
15	I intend to discuss end-of-life issues with my doctor in the next 6 months.	1	2	3	4
16	I feel the need to talk to my doctor about end-of-life issues.	1	2	3	4
17	I want to talk to my doctor about the options for end of life care.	1	2	3	4
18	I wanted to have this discussion but practical barriers (e.g. costs, mobility, transportation) prevented me from doing so.	1	2	3	4
19	I do not have the time to talk to my doctor about these issues.	1	2	3	4
20	I do not know enough about end-of-life issues to be able to discuss it with my doctor.	1	2	3	4
21	I think it will be easy to discuss end-of-life issues with my doctor.	1	2	3	4
22	I keep putting it off.	1	2	3	4
23	I do not like to think about these things.	1	2	3	4
24	My doctor does not have time for these discussions.	1	2	3	4
25	I tried to talk about it but my doctor did not want to.	1	2	3	4
26	If I wanted to discuss end-of-life issues with my doctor I could do so.	1	2	3	4
27	My family thinks that I should discuss end-of-life issues with my doctor.	1	2	3	4

28	I think it will be difficult to discuss end-of-life issues with my doctor.	1	2	3	4
28.	What was the most important factor that made you decide not to speak to your doctor about end of life issues?				

Section 2: Signing a living will

29.	In the past six months I have written a living will.	YES	NO

30.	Is this the first time you have written a living will.	YES	NO

If 'YES' to Q.29 OR Q.30, then proceed. If 'NO' then go to Q 40.

31.	Does your living will speak about resuscitation and the Do-not-attempt- to resuscitate order (DNAR)?	YES	NO

	The following questions are about your experience with signing a living will.	Strongly agree	Agree	Disagree	Strongly Disagree
32.	I am satisfied that I have signed the living will.	1	2	3	4
33.	Signing a living will was easy.	1	2	3	4
34.	I chose to sign a living will.	1	2	3	4
35.	It was difficult for me to sign a living will.	1	2	3	4
36.	My family thinks that I should sign a living will.	1	2	3	4
37.	I am content that I have signed the living will.	1	2	3	4
38.	My doctor thinks that I should sign a living will.	1	2	3	4
39.	What was the most important factor that made you decide to sign a living will?				

If 'NO' to Q. 29 OR Q.30 then answer the following questions. If you had answered 'YES' proceed to the next section.

		Strongly agree	Agree	Disagree	Strongly Disagree
40.	I plan to sign a living will.	1	2	3	4
41.	I intend to sign a living will in the next 6 months.	1	2	3	4
42.	I feel the need to sign a living will.	1	2	3	4
43.	I want to sign a living will.	1	2	3	4
44.	I wanted to sign a living will but practical barriers (e.g. costs, mobility, transportation) prevented me from doing so.	1	2	3	4
45.	I do not have the time to sign a living will.	1	2	3	4
46.	I do not know enough about living wills.	1	2	3	4
47.	I think it will be easy for me to sign a living will.	1	2	3	4
48.	I do not like to think about these things.	1	2	3	4
49.	I keep putting it off.	1	2	3	4
50.	My doctor and/or my family do not have time to discuss the living will.	1	2	3	4
51.	I tried to talk about signing a living will but my doctor and/ or family did not want to.	1	2	3	4
52.	If I wanted to sign a living will I could do so.	1	2	3	4
53.	My family thinks that I should sign a living will.	1	2	3	4
54.	I think it will be difficult to sign a living will.	1	2	3	4
55.	My doctor thinks that I should sign a living will.	1	2	3	4
56.	What was the most important factor that made you decide not to sign a living will?				

Section 3: Basic Demographic Information

57.	Your occupation at the time of retirement?				
58.	Have you had any new serious health problems in the past 6 months?			YES	NO
59.	How many times have you seen your doctor in the past 6 months?	0	1-2	3-5	6 and over

Section 4: Your views on different health-related issues.

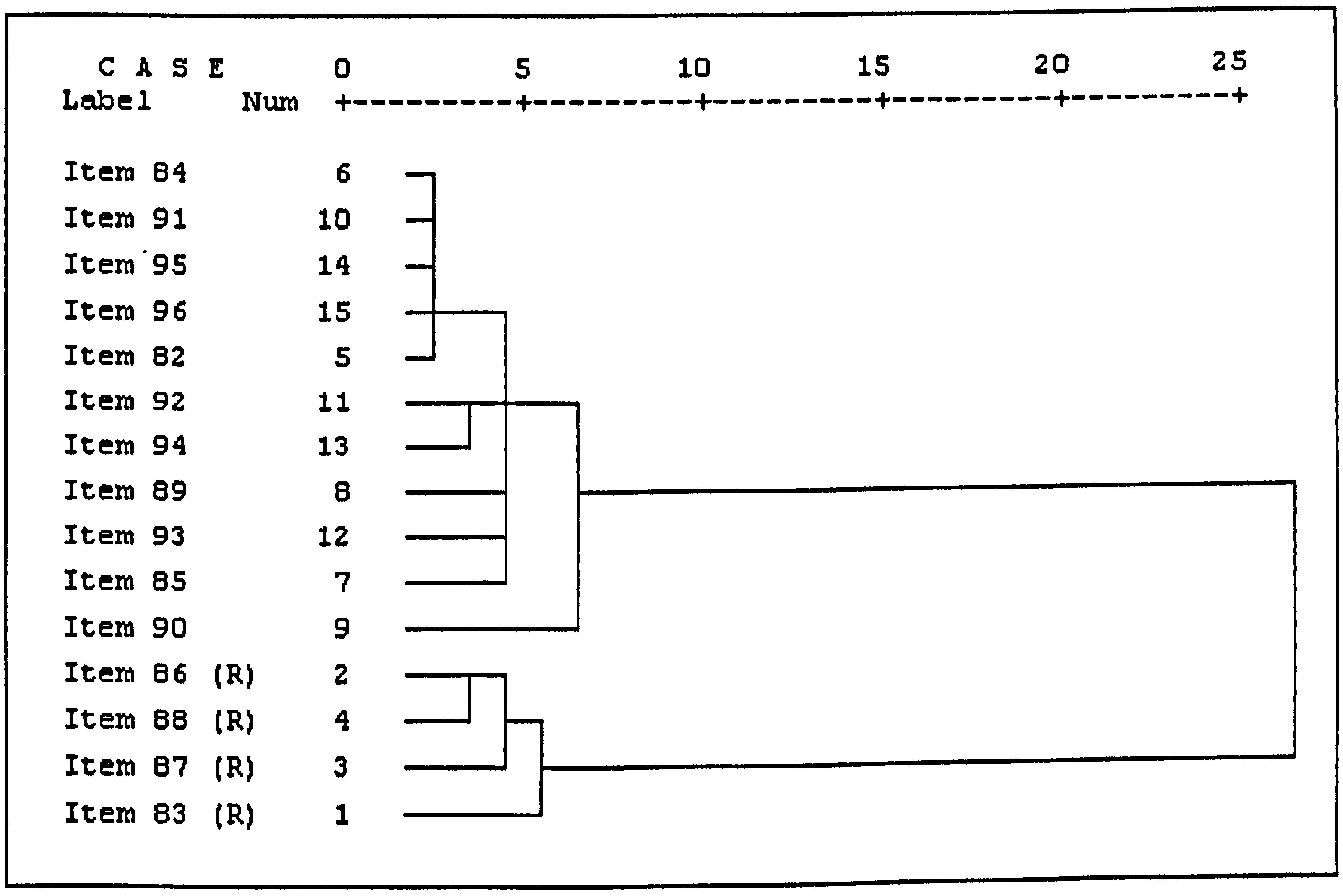
Please circle the number that represents the extent to which you disagree or agree with the following statements.

		Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
60.	If I get sick, it is my own behaviour that determines how soon I get well again.	1	2	3	4	5	6
61.	No matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
62.	Having regular contact with my doctor is the best way for me to avoid illness.	1	2	3	4	5	6
63.	Most things that affect my health happen to me by accident.	1	2	3	4	5	6
64.	Whenever I don't feel well, I should consult a medically trained professional.	1	2	3	4	5	6
65.	I am in control of my health.	1	2	3	4	5	6
66.	My family has a lot to do with my becoming sick or staying healthy.	1	2	3	4	5	6
67.	When I get sick I am to blame.	1	2	3	4	5	6
68.	Luck plays a big part in determining how soon I will recover from an illness.	1	2	3	4	5	6
69.	Health professionals control my health.	1	2	3	4	5	6
70.	My good health is largely a matter of good fortune.	1	2	3	4	5	6
71.	The main thing which affects my health is what I myself do.	1	2	3	4	5	6
72.	If I take care of myself, I can avoid illness.	1	2	3	4	5	6
73.	When I recover from an illness, it's usually because other people (for example, doctors, nurses, family friends) have been taking care of me.	1	2	3	4	5	6
74.	No matter what I do, I'm likely to get sick.	1	2	3	4	5	6

75.	If it's meant to be, I will stay healthy.	1	2	3	4	5	6
76.	If I take the right action, I can stay healthy.	1	2	3	4	5	6
77.	Regarding my health, I can only do what my doctor tells me to do.	1	2	3	4	5	6

Thank you for your help in completing the questionnaire. Please return the questionnaire in the **FREEPOST** envelope provided. Please feel free to contact me on **01483 68286** if you have any questions or concerns from answering any of the questions.

APPENDIX 11 - DENDROGRAM OF THE 2 CLUSTER SOLUTION OF THE DEATH ANXIETY SCALE



APPENDIX 12: ADVERT FOR STUDY 3

UniS

YOUR OPINION COUNTS!

Challenges of Ageing

At the Department of Psychology, University of Surrey we are conducting research into the challenges of ageing and medical decision-making in the later stages of life. The aim of our study is to find out how we can help people have good discussions with their doctors, nurses and family members about these difficult issues.

Volunteers are needed to participate in a discussion on the challenges of ageing and healthcare in the later stages of life. The discussion takes about 1½ hours, including breaks for refreshments. Volunteers will receive £20 for participating in the discussion.

Volunteers should be aged 65 or over. Anyone interested in finding out more about the study should contact:

Tushna Vandrevala
Department of Psychology,
University of Surrey, Guildford, Surrey GU2 7XH
Ph: 01483-682886
Email : t.vandrevala@surrey.ac.uk

This project is approved by the University of Surrey Advisory Committee on Ethics and is being funded by the Nuffield Foundation.

APPENDIX 13: INFORMATION SHEET FOR STUDY 3

Challenges of ageing: participant information sheet

What is the study about and who are we?

This study is investigating older people's views about the challenges of growing older and their views about healthcare. Advances in medical technology can prolong life and defer death. We wish to talk to you about your thoughts and preferences about these medical technologies. We are particularly interested in studying older people who are not in hospital, because this is a good time for people to think about and make decisions about the kind of care they would like to receive in the later stage of their life. The aim of our study is to find out how we can help people have good discussions with their doctors, nurses and family members about these difficult issues.

This study is part of a research project being conducted in the University of Surrey and funded by the Nuffield Foundation, under the direction of Professor Sarah Hampson (a health psychologist), Professor Sara Arber (a sociologist) Professor Hilary Thomas (an oncologist). Tushna Vandrevala and Tom Daly will be working directly with the people who participate in the study.

What will you be asked to do?

Those volunteering to participate in the study will be asked to take part in a group discussion with other older people on the subject of challenges of ageing including medical decision-making in later life. It is estimated that the discussion will take about 1 ½ hours, including breaks for refreshments. The discussion will be lead by Tom and Tushna.

Benefits and Risks

No one particularly likes to think or talk about ageing and medical decision-making in later life. We appreciate this, and therefore value your participation even more because we believe that there are great benefits of a study such as ours for improving health care for senior citizens.

On a personal level, talking about these sensitive issues and hearing others share their opinions may turn out to be an interesting and beneficial experience. Further, this study will help us to find ways to improve communication between patients, doctors and nurses about these difficult topics. As a result, patients' wishes are more likely to be heard and acted upon. Also as compensation for having participated in the study a sum of £20 will be given to participants.

We appreciate that answering some of the questions could be upsetting and distressing for you. You are under no pressure to complete the discussion and you may withdraw at any time, without providing an explanation.

All the information you provide will be stored and handled with the strictest confidence and anonymity, in accordance with the Data Protection Act (1998). We will never present an individual's answers so nothing we report could be traced back to you.

We will provide you with names and contact details of organisations that might be helpful to you if you decide you would like to find out more about medical decision-making in later life.

How to contact us?

For further information about the project please feel free to contact:
Tushna Vandrevala, Department of Psychology, University of Surrey, Guildford, Surrey GU2 7XH
Ph: 01483-682886 Email : t.vandrevala@surrey.ac.uk

Please feel free to take time to think about whether or not to participate in the study, or to discuss it with someone before deciding.

APPENDIX 14: FOCUS GROUP GUIDE

Summary outline for facilitators for group discussion

- Introduce self and assistant, say something about our roles.
- Introduce the topic, what it is about
- Talk about how the group discussion will work – some questions. Mainly want to hear their views. To help you discuss these we have some questions that we would like you to discuss. We are also interested in talking about issues that you raise yourselves.
- Tape recording –Say what will happen to the tapes and who hears them
- Confidentiality – only researchers have access to tapes and transcripts; hope will also remain confidential to group
- Anonymity – won't use names or location in any reports
- Distressing topic – can stop, can leave, can talk to researcher individually afterwards or at later time, support agencies to contact in participants pack
- Should last an hour to an hour and a half.

Part 1: Healthcare challenges of ageing

1) Briefly introduce yourself and tell us why you are here and wanted to participate in this discussion group.
2) We will spend the next couple of minutes briefly talking about the challenges of ageing, in terms of health care. We will follow the same structure, where everyone with get a chance to speak in order).

If anything on dying, death, bereavements or communication is mentioned ...follow that through.

<u>Prompts</u>

- What about end-of-life care or care in the later stages of life? Is it something that you think about? Why?
- Do you actively think about it or do not want to think about it?
- Is it something you talk about with anyone? If yes, in which instances have you discussed it and with whom?

Part 2: CPR and the DNAR order

We will move on the next section where we will talk about medical technologies that are used to prolong life. 'Sweeping advances in medical technology can be used to prolong life. The life prolonging technology used in medical sciences is vaste. Today we merely wish to discuss CPR otherwise called Cardiopulmonary Resuscitation (picture prompt passed around). I am sure most of you are familiar with this from watching TV (E.G. Casualty and ER). I will briefly describe this to you."Cardiopulmonary Resuscitation (CPR) means that when a person's heart and breathing stop, it is sometimes possible to try to restart their heart and breathing with emergency treatment by pushing firmly on the chest, using electric shocks, mouth-to-mouth' breathing"

1) What is the first thing that comes to mind when we talk about this particular life-prolonging technology. What is your opinion on this procedure?

You may also be aware that there is a 'CPR for all policy' in hospitals now. "The CPR for all policy in hospitals ensures that anyone who suffers a cardiac arrest in hospital will have CPR conducted on them. The only way CPR will not be conducted on a person is if the doctor or consultant in charge puts a DNAR (Do Not attempt to Resuscitate) order on the notes of the patient. Medical and legal documents suggest that this should happen after consultation with the patient."

2) What are your thoughts about the CPR for all policy and the DNAR policy?
3) Success and recovery from CPR?
4) Who should make this decision?
5) What factors should be taken into account while making these decisions?
6) When is the best time to think about and make arrangements?
7) What do you think the implications of these advancements are for you and your healthcare?

Part 3: Advance care planning

1) How can individuals ensure that they dying process is according to their wishes?

Description provided to participants. (Living will, discussion with healthcare practitioners and family).

Discuss with doctors

2) Why would you choose to talk about these issues with your GP and/or other medical professionals?
3) How easy would it be for you to talk about medical care for your final stages of life with your doctor?
4) What problems do you anticipate?
5) What motivated you to do it?
6) Why have you not discussed these issues with your doctor
7) If you have discussed it can you tell us a bit about it and offer suggestions, based on your experience?

Living wills

1) Do you have any views about living wills or advance directives? (Explain if they have not heard of them).
2) To what extent do you think a living well offers people with terminal conditions some kind of assurance?
3) How easy would it be for you to sign a living will
4) What problems do you anticipate?
5) What motivated you to do it?
6) Why have you not signed one
7) If you have signed a living will, can you tell us a bit about it and offer suggestions based on your experience

Discuss with family members

1) To what extent do you think taking to the family offers people with terminal conditions some kind of assurance?
2) How easy would for you to talk to your family
3) What problems do you anticipate?
4) What motivated you to do it?
5) Why have you not discussed these issues with your family?
6) If you have spoken to your family, can you tell us a bit about it and offer suggestions based on your experience.

Debriefing

As a result of the discussion we have had, what are your feelings and thoughts about this discussion, our research or any observations you have made.

APPENDIX 15: FOCUS GROUP CONSENT FORM

UniS

University of Surrey
Department of Psychology

CONSENT FORM

I, the undersigned voluntarily agree to take part in the study on **'Challenges of Ageing'**

I have read and understood the information sheet provided. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given.

I understand that all personal data from this study will be stored and handled with the strictest confidence and anonymity, in accordance with the Data Protection Act (1998).

I understand that I am free to withdraw from the study at any time without reason and needing to justify my decision.

I understand that I will receive the sum of £20 to compensate me for my time and travel to attend the focus group.

I confirm that I have read and understood the above and freely consent to participate in the study.

Name of volunteer ....
Signed ....
Date ....
Address ....
....
Telephone Number ....

Name of witness ....
Signed ....

Would you like to be contacted for further studies, on this topic?

Yes, I would like to be contacted   No, I do not wish to be contacted.

APPENDIX 16 – FOCUS GROUP DEMOGRAPHIC SHEET

ABOUT YOU

NAME	
ADDRESS POSTCODE	
PHONE	
GENDER	Male Female
AGE	65-69 70-74 75-79 80-84 85-89 90-94
MARITAL STATUS	Single Married Separated Widowed Currently living with a partner
HIGHEST EDUCATIONAL ATTAINMENT	Less than secondary school Secondary school College/Post-secondary University/Graduate Post Graduate
CURRENT EMPLOYMENT STATUS	Working full time Working part time Unemployed Retired Others ____________
OCCUPATION AT THE TIME OF RETIREMENT	
RELIGION	Christianity (which church you belong to__________) Hinduism Islam Jewish Buddhism Others________ None
ETHNICITY	White South-Asian South-east Asian African Other __________
RECRUITED FROM	

ABOUT YOUR FAMILY

Who do you live with	Alone Spouse/ partner Family Friends Institutional setting

ABOUT YOUR HEALTH

Do you have any long-term illness health problem or disability, which limits your daily activities?	YES	NO
If yes, what is it?		
Have you been admitted in the hospital in the past year?	YES	NO
If yes, indicate for what purpose you were admitted		

How would you rate your health?			
Very good	Good	Poor	Very poor

APPENDIX 17: FOCUS GROUP CPR WRITE UP

What is CPR?

Cardiopulmonary arrest means that a person's heart and breathing stop. When this happens, it is sometimes possible to try to restart their heart and breathing with emergency treatment called CPR.

CPR might include:

- repeatedly pushing down very firmly on the chest;
- using electric shocks to try to restart the heart;
- 'mouth-to-mouth' breathing; and
- inflating the lungs through a mask over the nose and mouth or tube inserted into the windpipe.

Is CPR tried on everybody whose heart and breathing stop?

When the heart and breathing stop unexpectedly, for example if a person has a serious injury or heart attack, the healthcare team will try CPR if it might help. A person's heart and breathing also stop working as part of the natural and expected process of dying. If people are already very seriously ill and near the end of their life, there may be no benefit in trying to revive them each time their heart and breathing stop. This is particularly true when patients have other things wrong with them that mean they don't have much longer to live. In these cases, restarting their heart and breathing may do more harm than good by prolonging the pain or suffering of someone who is soon to die naturally.

Do people get back to normal after CPR?

Each person is different. A few patients make a full recovery, some recover but have health problems and, unfortunately, most attempts at CPR do not restart their heart and breathing despite the best efforts of everyone concerned. It depends on why their heart and breathing stopped working and the patient's general health. It also depends on how quickly their heart and breathing can be restarted.

Patients who are revived are often still very unwell and need more treatment, usually in a coronary care or intensive care unit. Some patients never get back the level of physical or mental health they enjoyed before the cardiopulmonary arrest. Some have brain damage or go into a coma. Patients with many medical problems are less likely to make a full recovery. The techniques used to restart the heart and breathing sometimes cause side effects, for example, bruising, fractured ribs and punctured lungs.

What is the chance of CPR reviving me if I have a cardiopulmonary arrest?

The chance of CPR reviving you will depend on: why your heart and breathing have stopped; any illnesses or medical problems you have (or have had in the past); and the overall condition of your health.

Attempted CPR is successful in restarting the heart and breathing in about 4 out of 10 patients. On average, 2 out of 10 patients survive long enough to leave hospital. The figures are much lower for patients with serious underlying conditions. It is important to remember that these only give a general picture and not a definite picture of what you can expect. Everybody is different and the healthcare team will explain what CPR could do for you.

Does it matter how old I am or that I have a disability?

No. What is important is: your state of health; your wishes; and the likelihood of the healthcare team being able to achieve what you want. Your age alone does not affect the decision, nor does the fact that you have a disability.

Who will decide about CPR?

You and your doctor will decide whether CPR should be attempted if you have a cardiopulmonary arrest. The healthcare team looking after you will look at all the medical issues, including whether CPR is likely to be able to restart your heart and breathing if they stop, and for how long. It is beneficial to attempt resuscitation if it might prolong your life in a way that you can enjoy. Sometimes, however, restarting people's heart and breathing leaves them with a severe disability or only prolongs their suffering. Prolonging life in these circumstances is not always beneficial. Your wishes are very important in deciding whether resuscitation can benefit you, and the healthcare team will want to know what you think. If you want, your close friends and family can be involved in discussions. In most cases, doctors and their patients agree about treatment where there has been good communication.

What if I don't want to decide?

You don't have to talk about CPR if you don't want to, or you can put discussion off if you feel you are being asked to decide too much too quickly. Your family, close friends and carers might be able to help you make a decision you are comfortable with. Otherwise, the doctor in charge of your care will decide whether or not CPR should be attempted, taking account of things you have said.

What if we haven't decided and I have a cardiopulmonary arrest?

The doctor in charge of your care will make a decision about what is right for you. Your family and friends are not allowed to decide for you. But it can be helpful for the healthcare team to talk to them about your wishes. If there are people you do (or do not) want to be asked about your care, you should let the healthcare team know.

I know that I don't want anyone to try to resuscitate me. How can I make sure they don't?

If you don't want CPR, you can refuse it and the healthcare team must follow your wishes. You can make a living will (also called an 'advance directive') to put your wishes in writing. If you have a living will, you must make sure that the healthcare team knows about it and puts a copy of it in your records. You should also let people close to you know so they can tell the healthcare team what you want if they are asked.

If it is decided that CPR won't be attempted, what then?

The healthcare team will continue to give you the best possible care. The doctor in charge of your care will make sure that you, the healthcare team, and the friends and family that you want involved in the decision know and understand the decision, unless you don't want to talk about it. There will be a note in your health records that you are 'not for cardiopulmonary resuscitation'. This is sometimes called a 'do-not-attempt-resuscitation' or DNAR decision.

What about other treatment?

A DNAR order is about CPR **only** and you will receive all the other treatment you need.

What if I want CPR to be attempted, but my doctor says it won't work?

Although nobody can insist on having treatment that will not work, no doctor would refuse your wish for CPR if there was any real possibility of it being successful. If there is doubt whether CPR might work for you, the healthcare team will arrange a second medical opinion if you would like one. If CPR might restart your heart and breathing, but is likely to leave you severely ill or disabled, your opinion about whether these chances are worth taking is very important. The healthcare team must listen to your opinions and to the people close to you if you want them involved in the discussion.

APPENDIX 18: LETTER TO THE GP FOR STUDY 4

UniS
University of Surrey
Department of Psychology

Dear Dr………,

Following our meeting last week, I promised to provide you details of the study in writing. I will be happy to go visit you again to discuss any points of difficulty should these emerge..

Recruitment goal. Our goal is to recruit 24 participants. We want to recruit 3 men and 3 women in each of 4 age categories: 65-69, 70-74, 75-79 and over 80.

Inclusion criteria. Participants must be aged over 65, living in the community, they may or may not have a chronic condition, and they must be able to participate in an interview study in English.

Exclusion criteria. We do not wish to interview older people who are clinically depressed, recently bereaved, cognitively impaired or alcoholics as the subject may be distressing for them.

Your database needs to be searched with these inclusion and exclusion criteria. I appreciate you may not be able to pick up things like recent bereavement. We will screen potential participants ourselves as a double check.

Sending letters to potential participants.. Previous experience has shown us that to get this required response rate, we will need to send out at least 3 times the number of letters, that is 72 invitations in total, with 18 in each age category (9 men and 9 women). We hope that sufficient numbers of participants will be recruited from this first wave of letters. However, it may be necessary to send out more letters in a second wave.

Random sampling. If you are able to identify more than 9 men and 9 women in each of the four age categories above, then we have a procedure we would like you to follow to decide who to send letters to. (1) Identify the pool of all the eligible individuals in a particular age and sex category. (2) If there are more than 9, then select 9 from the total at random. These is done by dividing the total number you have identified in this age/sex category who are eligible (e.g., 27) and dividing this number by 9 (27/9 = 3). Send the letter to every third person. Keep track of how many people were identified at step (1). Keep track of who was sent a letter in case we have to go back to this pool for a second wave of letters

Patients identified from records as meeting our inclusion/exclusion criteria will be sent a letter by you (supplied and paid for by us) telling them about the project and inviting them to contact us for further information using the postage paid reply envelope and form provided. A copy of this letter is enclosed. We need to keep track of the number of letters sent out, so that we can calculate the participation rate. Please could you ensure that the schedule is completed and returned to us after the selection is made.

As agreed we shall pay the practice £25 per recruited participant as compensation for administrative costs to your practice. Further, we will provide the practice with postage and stationary.

Thank you very much for your help in this project. Please feel free to contact Tushna Vandrevala (t.vandrevala@surrey.ac.uk; telephone - 01483 682886) or me (t.daly@surrey.ac.uk@surrey.ac.uk; telephone - 01483 689292) for any further details.

Thank you for your help and time. Your help with this project is very much appreciated.

Yours sincerely,

Tushna Vandrevala
Department of Psychology
University of Surrey
Guildford GU2 7XH
t.vandrevala@surrey.ac.uk
01483 682886

Participant numbers

	65-69		70-74		75-79		80 +	
	male	female	male	female	male	female	male	female
No of participants in the initial pool meeting inclusion/exclusion criteria								
Number of letters send out								

APPENDIX 19: LETTER FROM GP SENT FOR PROSPECTIVE PARTICIPANTS

Patient's name and address GP Practice Letterhead

Date
Dear (Patient's name)

I am writing to let you know about an opportunity to take part in a study being conducted by the University of Surrey on 'Older people and their families: Autonomy and Decision Making in Later Life'. I believe that this is an important study that will help patients, their families and their doctors to ensure that older people receive medical care in accordance with their wishes.

In brief, the researchers would like to conduct an interview with you and, if possible, a family member of your choice. These interviews would take about an hour and half in total and would be conducted by two researchers coming to your home. The questions would be about medical advances in health care, life-prolonging technologies and discussing end-of-life issues with doctors and family members. This work is sponsored by the Nuffield Foundation and is being directed by Professors Hampson, Arber and Thomas at the University of Surrey.

It would be very helpful if you would reply to this invitation using the pre-paid acceptance sheet enclosed and return it to the Department of Psychology, University of Surrey. You will be under no obligation to participate. If you do not want to take part, you will not be contacted further.

Please return the acceptance sheet as soon as possible and I hope you will be interested in this valuable study.

Yours sincerely,

Dr.'s Name and address

Code

Please return this to:

Department of Psychology, University of Surrey, Guildford GU2 7XH using the FREEPOST envelope provided.

Older people and their families: Autonomy and Decision Making in Later Life

☐ I would like to learn more about this study

Name: ....

Address: ....
....
....
....
Postcode..

Phone: ....
Good times to ring: ....
....
E-mail: ....

Age **65-69** ☐ **70-74** ☐ **75-79** ☐ **80-+** ☐

Male ☐ **Female** ☐

☐ I do not wish to be contacted about this study

APPENDIX 20: OLDER PERSON'S INFORMATION SHEET FOR STUDY 4

Older People and their families: Autonomy and decision-making in later life.

You are being asked to take part in a research study being conducted at the Department of Psychology, University of Surrey. Before you decide whether or not to participate, it is important that you understand why the research is being done and what you will be asked to do. Please take time to read this information sheet carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or you would like more information.

What is the purpose of the study?

This study is investigating older people's views about the challenges of growing old and their views about healthcare. Advances in medical technology can now keep people alive for longer. We wish to talk to you about your thoughts and preferences about these medical technologies and how you wish to be involved in your medical decision making in the later stages of life. We are particularly interested in studying older people who are not in hospital, because this is a good time for people to think about and make decisions about the kind of care they would like to receive. The aim of our study is to find out how we can help people have good discussions with their doctors, nurses and family members about these difficult issues.

Who are we?

This study is part of a research project being conducted in the University of Surrey under the direction of Professor Sarah Hampson (a health psychologist), Professor Sara Arber (a sociologist) Professor Hilary Thomas (an oncologist). Tom Daly and Tushna Vandrevala will be working directly with the people who participate in the study.

Who is funding this research?

This research is being supported by the Nuffield Foundation. Their financial support pays for the staff involved. This study has been approved by the South West Surrey Local Research Ethics Committee.

What will I be asked to do?

You will be interviewed by the researchers on decision making in the later stages of life. You will be asked about your views and feelings on medical technologies used to prolong life and the degree to which these issues should be discussed with doctors and family members. Further, you will be given some hypothetical scenarios of people involved in decisions at the end-of-life and be asked to make some decisions.

In addition, you will be asked to nominate a 'confidant' who can either be a family member or a trusted friend who you would like involved in this decision making process. However, you are under no pressure to nominate a person and can still take part in the study without a confidant. If you do nominate a confidant they will be asked similar questions. It is estimated that the interview will last 1 ½ hours.

Do I have to take part?

It is entirely up to you to decide whether to take part or not. If you decide to take part, please sign the enclosed informed consent form and return it in the stamped, addressed envelope provided. Alternatively, you can contact us and we can provide you with further details about the study and answer any questions or queries you may have. If you decide to take part, you can withdraw from the study at any time, without having to provide any reasons.

What are the possible risks and benefits of taking part?

No one particularly likes to think or talk about ageing and decision-making in later life. We appreciate this, and therefore value your participation even more because we believe that there are great benefits of a study such as ours for improving health care for senior citizens.

On a personal level, talking about these sensitive issues and hearing others share their opinions may turn out to be an interesting and beneficial experience. Further, this study will help us to find ways to improve communication between patients, doctors and nurses about these difficult topics. As a result, patients' wishes are more likely to be heard and acted upon.

We appreciate that answering some of the questions could be upsetting. You may choose not to answer any of the questions, if you prefer not to.

Participants in our previous studies have found the experience a beneficial and valuable experience.

Will my taking part in the study be kept confidential?

All the information you provide will be stored and handled with the strictest confidence. With your permission, we will tape record the interview and transcribe it. We will use a code number instead of your name on all the information you provide. Only people working on the study will have access to the data. We will never present an individual's answers in a way that could be traced back to you. With your permission, we will inform your doctor that you are taking part in the study.

What if I have a complaint?

If you have any complaints about the study, you should contact the head of the project, Prof. Sarah Hampson (Tel; 01483 689266, email: s.hampson@surrey.ac.uk) or Tushna Vandrevala (Tel: 01483 682886, email: t.vandrevala@surrey.ac.uk) or Tom Daly (Tel: 01483 689292, email: tom.daly@surrey.ac.uk). They can all be reached at the above address.

If you decide to participate, please contact us at any time throughout the study if you have any questions and concerns. Thank you for considering our study and, if you do participate, thank you very much for your help with the study.

Tushna Vandrevala. Tel: 01483 682886, email: t.vandrevala@surrey.ac.uk

APPENDIX 21: CONFIDANT'S INFORMATION SHEET

Older People and their families: Autonomy and decision-making in later life.

You are being asked to take part in a research study being conducted at the Department of Psychology, University of Surrey. Before you decide whether or not to participate, it is important that you understand why the research is being done and what you will be asked to do. Please take time to read this information sheet carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or you would like more information.

What is the purpose of the study?

This study is investigating older people's views about the challenges of growing old and their views about healthcare. Advances in medical technology can now keep people alive for longer. We wish to talk to you about your thoughts and preferences about these medical technologies and how you wish to involve in your medical decision making in the later stages of life. We are particularly interested in studying older people who are not in hospital, because this is a good time for people to think about and make decisions about the kind of care they would like to receive. The aim of our study is to find out how we can help people have good discussions with their doctors, nurses and family members about these difficult issues.

Your older relative has nominated you as a family members who they wish to involve in this study. Please do contact us if you have any further questions regarding this study.

Who we are?

This study is part of a research project being conducted in the University of Surrey and funded by the Nuffield Foundation, under the direction of Professor Sarah Hampson (a health psychologist), Professor Sara Arber (a sociologist) Professor Hilary Thomas (an oncologist). Tom Daly and Tushna Vandrevala will be working directly with the people who participate in the study.

Who is funding this research?

This research is being supported by the Nuffield Foundation. Their financial suport pays for the staff involved. This study has been approved by the South West Surrey Local Research Ethics Committee.

What will I be asked to do?

Those volunteering to participate in the study will be interviewed by the researchers on decision making in the later stages of life. Questions will be asked on medical technologies used to prolong life and the degree to which these issues should be discussed with doctors and family members. Further, you will be given some hypothetical scenarios of people involved in decisions at the end-of-life and be asked to make some decisions.

In addition, participants will be asked to nominate a 'confidant' which can either be a family member or a trusted friend who you would like involved in this decision making process. You have been nominated to be the confidant. However, you are under no pressure to take part in the study. It is estimated that the interview will last 1 ½ hours.

Do I have to take part?

It is entirely up to you to decide whether to take part or not. If you decide to take part, please sign the enclosed informed consent form and return it in the stamped, addressed envelope provided. Alternatively, you can contact us and we can provide you with further details about the study and answer any questions or queries you may have. If you decide to take part, you can withdraw from the study at any time, without having to provide any reasons.

What are the possible risks and benefits of taking part?

No one particularly likes to think or talk about ageing and decision-making in later life. We appreciate this, and therefore value your participation even more because we believe that there are great benefits of a study such as ours for improving health care for senior citizens.

On a personal level, talking about these sensitive issues and hearing others share their opinions may turn out to be an interesting and beneficial experience. Further, this study will help us to find ways to improve communication between patients, doctors and nurses about these difficult topics. As a result, patients' wishes are more likely to be heard and acted upon.

We appreciate that answering some of the questions could be upsetting and distressing for you. You are under no pressure to participate and you may withdraw at any stage, without having to provide us an explanation.

Will my taking part in the study be kept confidential?

All the information you provide will be stored and handled with the strictest confidence. We will tape record the interview and transcribe it. However at this stage we will use a code number instead of your name. Only people working on the study will have access to information. We will never present an individual's answers so nothing we report could be traced back to you.

With your permission, we will inform your doctor that you are taking part in the study.

What if I have a complaint?

If you have any complaints about the study, you should contact the head of the project, Prof. Sarah Hampson (Tel; 01483 689266, email: s.hampson@surrey.ac.uk) or Tushna Vandrevala (Tel: 01483 682886, email: t.vandrevala@surrey.ac.uk)

If you decide to participate, please contact us at any time throughout the study if you have any questions and concerns. Thank you for considering our study and, if you do participate, thank you very much for your help with the study.

Tushna Vandrevala (Research assistant)
Tel: 01483 682886, email: t.vandrevala@surrey.ac.uk

APPENDIX 22: CONSENT FORM FOR OLDER PERSON AND CONFIDANT FOR STUDY 4

UniS

University of Surrey
Department of Psychology

Older People and their families: Autonomy and decision-making in later life.

Please sign and return this form.

CONSENT TO PARTICIPATE IN THE STUDY

I, the undersigned voluntarily agree to take part in the study on 'Older People and their families: Autonomy and decision-making in later life'. I have received and read a copy of the Participant Information Sheet. I have had the study explained to me and have had an opportunity to ask questions about the study. I understand that my participation is voluntary and that I may withdraw from the study at any time. I understand that all personal data from this study will be stored and handled with the strictest confidence and anonymity. This will not affect my medical care in any way. I agree to participate in this study as it has been described to me. I confirm that I have read and understood the above and freely consent to participate in the study.

Signature...Date
....

Name (please print)
....

APPENDIX 23: OLDER PERSON'S INTERVIEW SCHEDULE

1. What is the purpose of the study?

This study is investigating older people's views about the challenges of growing old and their views about healthcare. Advances in medical technology can now keep people alive for longer. We wish to talk to you about your thoughts and preferences about these LIFE PROLONGING medical technologies and how you wish to be involved in your medical decision making in the later stages of life. We are particularly interested in studying older people who are not in hospital, because this is a good time for people to think about and make decisions about the kind of care they would like to receive. The aim of our study is to find out how we can help people have good discussions with their doctors, nurses and family members about these difficult issues.

2. Tape recording

3. Confidentiality and Anonymity

5. Distressing topic - can withdraw at any time, support agencies to contact will be given

6. Last 30-40 min.

DATE OF INTERVIEW ____________________

GP CODE	
PARTICIPANT NO:	

NAME	
ADDRESS	
TOWN	

POST CODE	
PHONE	

AGE	**65-69**	**70-74**	**75-79**	**80 +**

Gender

Male ☐

Female ☐

ETHNICITY

WHITE ☐

CHINESE ☐

SOUTH ASIAN ☐

AFRICAN ☐

OTHERS ☐

MARITAL STATUS

MARRIED ☐

SEPARATED ☐

WIDOWER ☐

SINGLE ☐

EDUCATIONAL STATUS		**EMPLOYMENT STATUS**	
POST GRADUATION		WORKING FULL TIME	
GRADUATION		WORKING PART TIME	
METRICULATION		UNEMPLOYED	
SCHOOL CERTIFICATE		RETIRED	
NONE			

OCCUPATION AT RETIREMENT ____________________

RELIGION			
CHRISTIAN		**HOW RELIGIOUS**	
HINDU		Very religious	1
ISLAM			2
BUDDHIST			3
JEWISH			4
OTHERS		Not very religious	5
NO RELIGION			

How often do you pray? ____________________

LIVING ARRANGEMENTS Who do you live with?

ALONE	
SPOUSE/PARTNER	
FAMILY	
FRIENDS	
INSTITUTIONAL SETTING	

Long term illness	YES NO
Have you been admitted in the hospital in the past 5 years?	YES NO

How rate your health?

Very Good				Very Poor
1	2	3	4	5

Part 1: Views on life-prolonging measures

'Advances in medical technology have now made it possible to prolong life and these have been used to increase the life span of people'.

What are your thoughts about 'life prolonging' medical technologies that are used to increase life span at the final stages of life?

ATTITUDE
1 Very Opposed ☐
2 ☐
3 Very Accepting ☐

FOR SELF
1 life prolonged ☐
2 No life prolonged ☐
3 Did not bring it up ☐

1. VENTILATION

Do you understand what Ventilation entails? What are your thoughts about ventilation?

Highly opposed				Very acceptable
1	2	3	4	5

Why?____

2. ARTIFICIAL FEEDING

Do you understand what Artificial Feeding entails? What are your thoughts about artificial feeding?

Highly opposed				Very Acceptable
1	2	3	4	5

Why? ____

3. CARDIOPULMANARY RESUSCITATION

Do you understand what Resuscitation entails?
What are your thoughts about CPR?

Highly opposed				Very acceptable
1	2	3	4	5

4. CPR FOR SELF

1 Would like CPR ☐
2 Would not want CPR ☐
3 Did not state preference ☐

5. What are the values important to you when you thinking about life prolonging issues and advance care planning?
(Open ended question – prompted if no answer given)

	Yes/no
QUALITY OF LIFE	
FAMILY INTERESTS	
BURDEN ON FAMILY	
RETAINING CONTROL AND INDEPENDENCE	
RELIGIOUS CONVICTION	
DYING WITH DIGNITY	
PAIN	
AGE	

6. Empowerment and autonomy

How important is it for you to be involved in your own medical decisions?

Very imp				Not at all imp
1	2	3	4	5

7. Quality of life

People in the past have suggested that QUALITY OF LIFE be taken into account while making decisions regarding prolonging life.
OR (If mentioned previously), you previously suggested that QOL was important to you when making decisions to use life prolonging measures, would you like to expand on it).

What would you consider an accepted QUALITY OF LIFE?

Physical function	Both important	Mental function
1	2	3

8. Briefly tell me what your attitude towards death and dying is?
Or do you think about death and dying? What are your thoughts about these issues?

Prompt questions to include-
Is Death and dying something you think about?
When was the first time you thought about these issues?
Has your view changed over the past 10 years?

fear	
denial	
acceptance	
Others	

Part 2: Discussion with significant others (family members)

9. Choice of 'confidant' or significant other

Why did you choose this particular person

Only one available ☐
Family – Spouse, Daughter &c ☐
Other - specify ☐

10. What factors did you take into account? (open ended question)

Person knows me best ☐
Empathy and Support ☐
Previous Experience ☐
Confidentiality ☐
Practicality - Dispersed Family ☐
Other Qualities - specify ☐

11. Would this person have been your first choice? Is there anyone else in the family who you would discuss these issues with?

Spouse ☐
Daughter ☐
Son ☐
Brother/Sister ☐
Other ☐

12. Have you discussed Life-prolonging measures / end-of-life issues or care in the later stages of life with your confidant?

Yes ☐
No ☐

If YES

Why When Where How What With whom

13. Why did you choose to discuss these issues with your confidant? Or what prompted you to discuss these issues with your family member?

Age: when one grows older ☐
Personal experience with death ☐
When Health ☐
Prompted by doctor ☐
Prompted by family member ☐

14. Can you tell me how this conversation with your family member started and how it proceeded? (open ended question)

I initiated it ☐
He/she initiated it ☐
It just happened ☐
Watching TV ☐
Prompted by a book/article etc ☐

16. Was the conversation with your family member a formal or informal conversation?

FORMAL ☐
INFORMAL ☐

17. The events of the conversation or the story in terms of where, when and with whom and what prompted you to discuss these issues.

Where At home ☐
At a funeral ☐
At the cinema/theatre &c ☐

When		**Why**	
After the event	☐	Because I was troubled	☐
During the event	☐	Trying to make up my mind	☐
Some time later	☐	Trying to reassure my companion	☐

What Discussed and What not discussed

Hospice Care	☐	Funeral arrangements	☐
Pain relief	☐	Euthanasia	☐
Death with dignity	☐	Life prolongation	☐
Setting affairs in order	☐		

(D for discussed and ND for not discussed)

18. Were there any follow-up conversations?

Number of Times discussed Just the once ☐
Recurring theme ☐

19. Discussion vs. informing : Degree to which this was a discussion rather than a information providing exercise.

Tell them my views without regard to their opinions ☐
I would respect their views but do what I want ☐
I owe it to them to listen to their views. ☐
Listen but make up my own mind ☐
Half and half ☐

20. How did this conversation affect your confidant? Did this impose a burden on them or did it relieve them?

They felt relieved ☐
It imposed a burden on them ☐
No effect either way ☐

21. Barriers to communication (open ended question)

My reluctance ☐
Their resistance ☐
Opportunity to do so ☐
They live to far away ☐
No barrier ☐

22. What problems did you encounter? (open ended question)

Finding an opportunity ☐
I broke down ☐
They broke down ☐
Death and dying taboo subject ☐
No problems ☐

23. How did you deal with them? (open ended question)

Fixed a specific time ☐
Tried to reassure them ☐
Stressed the importance to me ☐
Did nothing ☐

24. Outcome of the conversation for you and for your confidant?

YOU		**CONFIDANT**	
Felt better	☐	Felt better	☐
Felt worse	☐	Felt worse	☐
No effect	☐	No effect	☐

25. How in your view would it be easier to discuss end of life issues with family members? (open ended question)

If one had prepared the ground ☐
If it was not a taboo ☐
Seize any opportunity - Funeral ☐
Over a meal ☐
TV/Drama programme ☐

26. What are the suggestions you would give someone who is discussing this with a family member? (open ended question)

Do not rush them ☐ Come straight to the point ☐
Sound them out first ☐ Make sure that they want to ☐

PARTICIPANTS WHO HAD NOT DISCUSSED THESE ISSUES WITH THEIR DOCTORS

If NO

27. Why did you choose not discuss these issues with your confidant?

- My reluctance ☐
- Their resistance ☐
- No opportunity ☐
- Taboo subject ☐

28. On what occasion will you discuss it with your confidant? (Open ended question)

- When I go in for an operation ☐
- When I feel like it ☐
- If they raise it ☐
- Never – I fear talking about death ☐
- Never – They fear talking about death ☐
- Prompted by this study ☐

If you did decide to discuss these issues with a family member imagine a hypothetical situation of how the conversation with proceed

HYPOTHETICAL SITUATION

Why When Where How What With whom

29. Why now?

- Age: when one grows older ☐
- Personal experience with death ☐
- Health ☐
- Before going into hospital ☐
- Prompted by doctor ☐
- Prompted by family member ☐

30. Can you tell me how you would initiate this conversation and how it will proceed ?

- I initiated it ☐
- He/she initiated it ☐
- It just happened ☐
- Watching TV ☐
- Prompted by a book/article etc ☐

31. Formal or informal conversation

FORMAL ☐
INFORMAL ☐

32. The events of the conversation or the story in terms of where, when and with whom and what prompted you to discuss these issues.

Where	At home	☐
	At a funeral	☐
	At the cinema/theatre &c	☐

When		**Why**	
After the event	☐	Because I was troubled	☐
During the event	☐	Trying to make up my mind	☐
Some time later	☐	Trying to reassure my companion	☐

What will be Discussed and What will not discussed

Hospice Care	☐	Funeral arrangements	☐
Pain relief	☐	Euthanasia	☐
Death with dignity	☐	Life prolongation	☐
Setting affairs in order	☐		

(D for discussed and ND for not discussed)

33. Would there be any follow-up conversations?

Number of Times Discussed	Just the once	☐
	Recurring theme	☐
	More than 5 times	☐

34. Discussion vs. informing : Degree to which this will be a discussion rather than a information providing exercise.

Tell them my views without regard to their opinions ☐
I would respect their views but do what I want ☐
I owe it to them to listen to their views. ☐
Listen but make up my own mind ☐
Half and half ☐

35. How did this conversation affect your confidant? Did this impose a impose a burden on them or did it relieve them?

They felt relieved ☐
It imposed a burden on them ☐
No effect either way ☐

36. Barriers you anticipate to communication

My reluctance ☐
Their resistance ☐
Opportunity to do so ☐
They live to far away ☐

37. What problems would you anticipate to encounter?

Finding an opportunity ☐
I broke down ☐
They broke down ☐
Death and dying - taboo subjects ☐

38. How will you deal with them?

Fixed a specific time ☐
Tried to reassure them ☐
Stressed the importance to me ☐

39. Outcome of the conversation for you and for your confidant?

YOU		CONFIDANT	
Felt better	☐	Felt better	☐
Felt worse	☐	Felt worse	☐
No effect	☐	No effect	☐

40. Would there be any follow up conversations?

Yes ☐
No ☐

41. How in your view would it be easier to discuss end of life issues with family members?

If one had prepared the ground ☐
If it was not a taboo ☐
Seize any opportunity - Funeral ☐
Over a meal ☐
TV/Drama programme ☐

42. Conclusion

As a result of the participating in this study, what are your feelings and thoughts about this discussion, our research or any observations you have made?

APPENDIX 24: CONFIDANT'S INTERVIEW SCHEDULE

1. What is the purpose of the study?
This study is investigating older people's views about the challenges of growing old and their views about healthcare. Advances in medical technology can now keep people alive for longer. We wish to talk to you about your thoughts and preferences about these LIFE PROLONGING medical technologies and how you wish to be involved in your medical decision making in the later stages of life. We are particularly interested in studying older people who are not in hospital, because this is a good time for people to think about and make decisions about the kind of care they would like to receive. The aim of our study is to find out how we can help people have good discussions with their doctors, nurses and family members about these difficult issues.

2. Tape recording
3. Confidentiality
4. Anonymity
5. Distressing topic - can withdraw at any time, support agencies to contact will be given
6. Part 1 will last 30-40 min.

In this interview, you have been nominated as a 'CONFIDANT' OR FAMILY MEMBER who may be consulted to make decisions on behalf of the older person. Some of the questions will be about your own views on life prolongation and others on your opinion for making these decisions on behalf of your family member.

DATE OF INTERVIEW ____________________

GP CODE	
PARTICIPANT NO:	

NAME	
ADDRESS	
TOWN	

POST CODE	
PHONE	

AGE	**65-69**	**70-74**	**75-79**	**80 +**

Gender

Male	
Female	

ETHNICITY
- WHITE ☐
- CHINESE ☐
- SOUTH ASIAN ☐
- AFRICAN ☐
- OTHERS ____________ ☐

MARITAL STATUS
- MARRIED ☐
- SEPARATED ☐
- WIDOWER ☐
- SINGLE ☐

HIGHEST EDUCATIONAL STATUS
- POST GRADUATION ☐
- GRADUATION ☐
- METRICULATION ☐
- SCHOOL CERTIFICATE ☐
- NONE ☐

EMPLOYMENT STATUS
- WORKING FULL TIME ☐
- WORKING PART TIME ☐
- UNEMPLOYED ☐
- RETIRED ☐

OCCUPATION AT RETIREMENT ____________________

RELIGION
- CHRISTIAN ☐
- HINDU ☐
- ISLAM ☐
- BUDDHIST ☐
- JEWISH ☐
- OTHERS ☐
- NO RELIGION ☐

HOW RELIGIOUS

Very religious	1
	2
	3
	4
Not very religious	5

How often do you pray? ____________________

LIVING ARRANGEMENTS Who do you live with?
- ALONE ☐
- SPOUSE/PARTNER ☐
- FAMILY ☐
- FRIENDS ☐
- INSTITUTIONAL SETTING ☐

Long term illness	YES NO
Have you been admitted in the hospital in the past 5 years?	YES NO

How rate your health?

Very Good				Very Poor
1	2	3	4	5

Part 1: Views on life-prolonging measures

'Advances in medical technology have now made it possible to prolong life and these have been used to increase the life span of people'.
What are your thoughts about 'life prolonging' medical technologies that are used to increase life span at the final stages of life?

ATTITUDE
1 Very Opposed ☐
2 ☐
3 Very Accepting ☐

FOR YOUR OLDER RELATIVE
1 life prolonged ☐
2 No life prolonged ☐
3 Did not bring it up ☐

4. VENTILATION

Do you understand what Ventilation entails? What are your thoughts about ventilation?

Highly opposed				Very acceptable
1	2	3	4	5

Why? ______________________________

5. ARTIFICIAL FEEDING

Do you understand what Artificial Feeding entails? What are your thoughts about artificial feeding?

Highly opposed				Very acceptable
1	2	3	4	5

Why? ______________________________

6. CARDIOPULMANARY RESUSCITATION

Do you understand what Resuscitation entails?
What are your thoughts about CPR?

Highly opposed				Very acceptable
1	2	3	4	5

4. CPR FOR YOUR OLDER RELATIVE

1 Would like CPR for my relative ☐
2 Would not want CPR for my relative ☐
3 Did not state preference ☐

5. What are the values important to you when you thinking about life prolonging issues and advance care planning?
(Open ended question – prompted if no answer given)

	Yes/no
QUALITY OF LIFE	
FAMILY INTERESTS	
BURDEN ON FAMILY	
RETAINING CONTROL & INDEPENDENCE	
RELIGIOUS CONVICTION	
DYING WITH DIGNITY	
PAIN	
AGE	

6. Empowerment and autonomy

How important is it for you to be want the older person involved in your own medical decisions?

Very imp				Not at all imp
1	2	3	4	5

7. Quality of life

People in the past have suggested that QUALITY OF LIFE be taken into account while making decisions regarding prolonging life.
OR (If mentioned previously), you previously suggested that QOL was important to you when making decisions to use life prolonging measures, would you like to expand on it).

What would you consider an accepted QUALITY OF LIFE?

Physical function	Both important	Mental function
1	2	3

8. Briefly tell me what your attitude towards death and dying is? Or do you think about death and dying?

Prompt questions to include-
Is Death and dying something you think about?
When was the first time you thought about these issues?
Has your view changed over the past 10 years?

fear ☐
denial ☐
acceptance ☐
Others ☐

Part 2: Discussion with significant others (family members)

9. Have you discussed Life-prolonging measures / end-of-life issues or care in the later stages of life with your confidant?

Yes ☐
No ☐

If YES

Why When Where How What With whom

10. Why did you choose to discuss these issues with your older relative? Or what prompted you to discuss these issues with your family member?

Age: when one grows older ☐
Personal experience with death ☐
When Health ☐
Prompted by doctor ☐
Prompted by family member ☐

11. Can you tell me how this conversation with your family member started and how it proceeded? (open ended question)

I initiated it ☐
He/she initiated it ☐
It just happened ☐
Watching TV ☐
Prompted by a book/article etc ☐

12. Was the conversation with your family member a formal or informal conversation?

FORMAL ☐
INFORMAL ☐

13. The events of the conversation or the story in terms of where, when and with whom and what prompted you to discuss these issues.

Where At home ☐
At a funeral ☐
At the cinema/theatre &c ☐

When		**Why**	
After the event	☐	Because I was troubled	☐
During the event	☐	Trying to make up my mind	☐
Some time later	☐	Trying to reassure my companion	☐

What Discussed and What not discussed

Hospice Care ☐
Pain relief ☐
Death with dignity ☐
Setting affairs in order ☐

Funeral arrangements ☐
Euthanasia ☐
Life prolongation ☐

(D for discussed and ND for not discussed)

14. Were there any follow-up conversations?

Number of Times discussed

Just the once ☐
Recurring theme ☐

15. Discussion vs. informing : Degree to which this was a discussion rather than a information providing exercise.

Tell them my views without regard to their opinions ☐
I would respect their views but do what I want ☐
I owe it to them to listen to their views. ☐
Listen but make up my own mind ☐
Half and half ☐

16. Did this impose a burden on them or did it relieve them?

They felt relieved ☐
It imposed a burden on them ☐
No effect either way ☐

17. Barriers to communication (open ended question)

My reluctance ☐
Their resistance ☐
Opportunity to do so ☐
They live to far away ☐
No barrier ☐

18. What problems did you encounter? (open ended question)

Finding an opportunity ☐
I broke down ☐
They broke down ☐
Death and dying: taboo subject ☐
No problems ☐

19. How did you deal with them? (open ended question)

Fixed a specific time ☐
Tried to reassure them ☐
Stressed the importance to me ☐
Did nothing ☐

20. Outcome of the conversation for you and for your confidant?

YOU		CONFIDANT	
Felt better	☐	Felt better	☐
Felt worse	☐	Felt worse	☐
No effect	☐	No effect	☐

21. How in your view would it be easier to discuss end of life issues with family members?
(open ended question)

If one had prepared the ground ☐
If it was not a taboo ☐
Seize any opportunity - Funeral ☐
Over a meal ☐
TV/Drama programme ☐

22. What are the suggestions you would give someone who is discussing this with a family member? (open ended question)

Do not rush them ☐
Sound them out first ☐
Come straight to the point ☐
Make sure that they want to ☐

PARTICIPANTS WHO HAD NOT DISCUSSED THESE ISSUES WITH THEIR DOCTORS

If NO

23. Why did you choose not discuss these issues with your confidant?

My reluctance ☐
Their resistance ☐
No opportunity ☐
Taboo subject ☐

24. On what occasion will you discuss it with your confidant? (Open ended question)

When I go in for an operation ☐
When I feel like it ☐
If they raise it ☐
Never – I fear talking about death ☐
Never – They fear talking about death ☐
Prompted by this study ☐

If you did decide to discuss these issues with a family member imagine a hypothetical situation of how the conversation with proceed

HYPOTHETICAL SITUATION

Why When Where How What With whom

25. Why now?

Age: when one grows older ☐
Personal experience with death ☐
Health ☐
Before going into hospital ☐
Prompted by doctor ☐
Prompted by family member ☐

26. Can you tell me how you would initiate this conversation and how it will proceed ?

I initiated it ☐
He/she initiated it ☐
It just happened ☐
Watching TV ☐
Prompted by a book/article etc ☐

27. Formal or informal conversation

FORMAL ☐
INFORMAL ☐

28. The events of the conversation or the story in terms of where, when and with whom and what prompted you to discuss these issues.

Where At home ☐
At a funeral ☐
At the cinema/theatre &c ☐

When
After the event ☐
During the event ☐
Some time later ☐

Why
Because I was troubled ☐
Trying to make up my mind ☐
Trying to reassure my companion ☐

What will be Discussed and What will not discussed

Hospice Care ☐
Pain relief ☐
Death with dignity ☐
Setting affairs in order ☐

Funeral arrangements ☐
Euthanasia ☐
Life prolongation ☐

(D for discussed and ND for not discussed)

29. Would there be any follow-up conversations?

Number of Times Discussed	Just the once	☐
	Recurring theme	☐
	More than 5 times	☐

30. Discussion vs. informing : Degree to which this will be a discussion rather than a information providing exercise.

Tell them my views without regard to their opinions ☐
I would respect their views but do what I want ☐
I owe it to them to listen to their views. ☐
Listen but make up my own mind ☐
Half and half ☐

31. How did this conversation affect your confidant? Did this impose a impose a burden on them or did it relieve them?

They felt relieved ☐
It imposed a burden on them ☐
No effect either way ☐

32. Barriers you anticipate to communication

My reluctance ☐
Their resistance ☐
Opportunity to do so ☐
They live to far away ☐

33. What problems would you anticipate to encounter?

Finding an opportunity ☐
I broke down ☐
They broke down ☐
Death and dying - taboo subjects ☐

34. How will you deal with them?

Fixed a specific time ☐
Tried to reassure them ☐
Stressed the importance to me ☐

35. Outcome of the conversation for you and for your confidant?

YOU		**CONFIDANT**	
Felt better	☐	Felt better	☐
Felt worse	☐	Felt worse	☐
No effect	☐	No effect	☐

36. Would there be any follow up conversations?

Yes ☐
No ☐

37. How in your view would it be easier to discuss end of life issues with family members?

If one had prepared the ground ☐
If it was not a taboo ☐
Seize any opportunity - Funeral ☐
Over a meal ☐
TV/Drama programme ☐

38. Conclusion

As a result of the participating in this study, what are your feelings and thoughts about this discussion, our research or any observations you have made?