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Older people and end of life choices : an exploration of the options and related discourses

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Older people and end of life choices.

An exploration of the options and related discourses.

Catharina P. Th. (Carolien) Lamers

Bangor University

Submitted in part fulfilment of the final degree award
Doctorate in Clinical Psychology
April 2012

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Acknowledgements

Where to start but with:

Pap, who travelled along in anticipation. When he started on *his* last journey, he showed me the way to continue on my adventure of life.

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NWCPP, who made a long held wish possible.

This part is complete.

Carolien Lamers

April 2012

Thesis Abstract

Older people and end of life choices.

An exploration of the options and related discourses.

With advance decisions currently being the only legal means of expressing ones wishes about the end of life in the UK, the literature revealed that the assumed benefits of having an advance decision, can be challenged. The *process* of discussing the choices and wishes for the end of life appeared to be considered more valuable by older people, than the *outcome* of having an advance decision.

With the debates about possible legalisation of euthanasia and assisted suicide ongoing in the UK, seven older people were interviewed to explore their position in this debate. The interviews were analysed using discourse analysis, with reference to the Foucauldian concepts of knowledge, power, subjectification and surveillance.

Three main discourses emerged: confused and conflicted, an aged death and voiceless in the debate. A patchy knowledge about the nature of the acts fed into conflicting discourses. A self-determination discourse was eroded by discourses that involved family and physicians in the decision-making process. The medicalisation of dying appeared endorsed at several levels, through the physicians' knowledge, power, subjectification and surveillance processes. An alternative dying discourse emerged where healing and growth in death were considered possible. For this healing and growth to occur, family were present and the medical gaze absent.

In the aged death discourse, participants talked about the anticipated changes in their physical and mental health before their death in old age. However, they expressed concern about becoming dependent on professional others and the quality of care they might receive at the end of their life. They appeared to disappear from any ‘gaze and surveillance’ and were concerned they would be treated like ‘objects’. Euthanasia and assisted suicide were considered as options that could provide a sense of control and independence at the end of life. It is possible that the position of older people in society and their worthiness of care and attention might have been internalised by older people and hence contributed to their consideration of euthanasia and assisted suicide.

The participants reported feeling voiceless in the debate, as they experienced difficulty engaging others in a debate about euthanasia and assisted suicide, attributing vulnerabilities to debating partners (children, friends, physicians), who would normally be considered as holding powerful positions. They expressed frustration about the fact that it appeared that arguments in favour of euthanasia and assisted suicide had to meet a ‘higher standard of rationality’, than the arguments presented against euthanasia and assisted suicide. Their confused knowledge about the exact nature of euthanasia and assisted suicide might also hamper their power position in any debate.

Psychologists need to remain vigilant about the impact of conflicting discourses the older person might express and critical of the impact societal discourses about ageing may have on the older person as well as the health and social care provision.

Literature review: Guidance for Authors



SOCIAL SCIENCE & MEDICINE

AUTHOR INFORMATION PACK

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Advance Decisions: can they deliver what they promise?

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Abstract

The number of people completing Advance Decisions (AD) remains low, despite efforts to increase the uptake through education initiatives. In an attempt to understand this finding, literature was reviewed regarding the underlying assumed benefits of ADs: increased sense of autonomy, expressing one's values and choices and having them adhered to, and assistance for decision makers. Findings from a range of studies challenged the view that these assumed benefits are achieved with ADs. However, an overarching theme in the views from research participants was a desire for (inter) connectedness, relating to the process of talking with family and multidisciplinary team members about wishes for the end of one's life. This principle might provide a useful angle when designing education programmes and when negotiating and implementing ADs. The current emphasis on how to increase the number of ADs seems to ignore the apparent more valued and valuable process of discussing and negotiating the end-of-life wishes with those we feel connected to.

Keywords: Advance directives, living wills, older adults, surrogates, autonomy, decision-making.

Introduction

As approximately two-thirds of all deaths are non-sudden and protracted (Abarshi et al., 2009), people have the opportunity to express their wishes, preferences and consent regarding possible end-of-life medical decisions in Advance Decisions (AD) ¹, which will be considered when they lack the capacity to make decisions. ADs are being endorsed via policies and legislation in countries across the world, e.g. the Patient Self Determination Act in the USA (Ali, 1999) and the Mental Capacity Act 2005 in England and Wales (Department of Constitutional Affairs, 2007). The merits of ADs are presented in most policy and research papers as self-evident implicit assumptions that favour the pursuit of completion of ADs (Golden et al., 2009; Salmond & David, 2005; Schicktanz, 2009).

These assumptions are that ADs:

- 1) enhance people's sense of autonomy;
- 2) facilitate people's expression of personal values and end-of-life choices;
- 3) increase the likelihood that the person's wishes will be followed.

There are also assumed benefits for the system around the person:

- 4) they assist the families in the end of life decision-making.
- 5) ADs can possibly decrease health care costs.

Although this final assumed benefit could be a motivating factor, this point will not be discussed further as there are few accurate data available.

Despite the assumed benefits of ADs, Jezewski et al. (2007) found in a systematic literature review that completion rates remain low, between 0.4 and 30% of the population, although

in Silveira et al. (2010) proxy survey a completion rate of 67% was found. In descriptive studies, completion rates are positively influenced by demographic factors such as being white, older and having a higher level of education, but there do not seem to be gender differences (Campbell et al., 2007; Salmond & David, 2005). Educational interventions designed to increase knowledge regarding ADs, from single-arm interventions to randomized control studies, had mixed results (Golden et al., 2009; Hamel et al., 2002; Lawrence, 2009; Molloy et al., 2000). Two systematic reviews (Bravo et al., 2008; Patel et al., 2004) found promising pooled odds ratio of 3.71 to 4.0 for randomized controlled studies, where combined interventions of oral information, direct counselling and multiple conversations between the person and health care professionals were most efficacious for completing ADs. Having a chronic health condition, like diabetes and heart disease, did not appear to influence the completion rate, following educational intervention. The completion rate was higher for a non-clinical population and nursing home residents. The limitations of these reviews are that the participants were predominantly Caucasian and Catholic and that all studies were conducted in the USA. There are no reliable data available for the number of completed ADs in the UK.

Can people be persuaded that a completed AD actually delivers the assumed benefits? The first four of the assumed benefits and relevant literature will be discussed in turn, in an attempt to shed more light on the apparent ambivalence of people towards writing an AD. This paper will focus on ADs as experienced by older adults (unless indicated otherwise) and for treatments of physical health conditions, rather than mental health conditions (e.g. dementia) where capacity might be questionable.

Search strategy

The Web of Knowledge, CINAHL, PsycINFO and Medline were searched using the search terms: “Advance Directives” or “Advance Decisions” and “Older People” or “Older Adults” combined with “completion” or “barriers”, published after 1990. A total of 34 relevant references were located. A hand search of reference lists and suggested articles by a referencing service resulted in a further 30 publications being identified, including quantitative and qualitative studies, expert opinions, legislation and professional guidance (All papers used summarised in Appendix 1).

Assumption 1: ADs enhance the person’s sense of autonomy.

ADs provide the opportunity to enhance personal autonomy, which in this context is defined as making decisions about end-of-life care, free from controlling interferences by others and personal limitations such as limited understanding, that prevent meaningful choice (Bravo et al., 2008; Campbell et al., 2007; DeLuca Havens, 2000).

The ability to complete an AD, free from controlling interference from others, was challenged by Mezey et al. (2000), who in their survey of 207 adult patients (average age 52, range 18-94) who had an AD, found that 37% of respondents said that they ‘thought they had to fill it out’. It was more likely that these people were Spanish speaking, less educated and of lower income level. Salmond and David (2005) found in their survey that half of their sample of adult patients (N=80) was not able to describe the nature of an AD in their own words, despite 81% stating that they had received relevant information. Two components of autonomous action (free from controlling influences and personal

limitations like knowledge) can be challenged, indicating that the reported completion rates may not always reflect true autonomous choice.

Nevertheless, for those who completed an AD, autonomy and control seemed to be relevant motivating factors. When Mezey et al. (2000) asked 207 patients for their motivation for completing an AD, 92% stated that ‘making up one’s own mind’ was the main reason for doing so. ‘Wanting to be in control of these decisions’ was a factor for 53% of 19 older respondents who had completed an AD in an experimental post-test-only control and randomized group design study (Hamel et al., 2002), while ‘having control over treatment decisions’ and ‘avoiding over-treatment’ were given as reasons by 14 participants who had completed ADs in the survey study by Salmond and David (2005). However, when DeLuca Havens (2000) questioned 210 people (average age 50; range 20-88), she found no difference in the desire for autonomy and self-determination between completers *and* non-completers, indicating that this motivation was not as decisive as assumed. Of those not completing ADs, 21% (N=65) to 38% (N=779) stated that ‘the family would decide what to do’ (Mezey et al., 2000; Salmond & David, 2005) and 30% thought ‘the doctor will do what is right’ (Mezey et al., 2000). Those willing for doctors to decide were more likely to have obtained a written AD only, rather than having had informal discussion with their relatives. This could indicate that they may have completed an AD at the behest of their physician.

Hamel et al. (2002) found that 12% (N=74) indicated ‘trusting others to decide’ as a reason for non-completion. Allowing (or selecting) others to make decisions about end-of-life care

can be seen as an act of choice and autonomy in and of itself (Salmond & David, 2005). Thirty-two older adults in the UK attending focus groups, described the above as the paradox between control and autonomy, and interdependence with the family (Seymour et al., 2004). Decker and Reed (2005) refer to this approach as ‘integrated moral reasoning’, a thinking style more typical in older adulthood whereby multiple views, contradictions and ambiguity are embraced. Apart from a possible developmental difference, this view could also be a cohort effect. Candib (2002) reflected in her theoretical paper, that expressing personal autonomy through ADs made sense in a western world-view, where society sees people as separate from each other, and values self-reliance, and where individualism and self-control are nurtured in order to maximize autonomy. This view has been translated into western medical practice, where the disclosure of diagnosis and prognosis are meant to enable the exercise of personal autonomy and control at the end of life. In many cultures, for example African American, Asian American and Latino, there is a greater emphasis on interdependence (Salmond & David, 2005). Family determination replaces self-determination and has a higher value than individualism. Candib referred to this as ‘autonomy in relation, embedded in collective interdependence’.

Using one’s autonomy not to write an AD, especially for non-white populations, could reflect the absence of reciprocal trust between the person and the community in which they receive health care (DeLuca Havens, 2000). People who did not write an AD, mainly Hispanic, less educated low-income patients, expressed their fear of putting their wishes in writing. They saw their already restricted and unequal access to health services further compromised by ADs (Mezey et al., 2000). African-Americans expressed a similar concern

and in their ADs they showed a strong preference for more aggressive end-of-life care, defined by Decker and Reed (2005) as e.g. mechanical ventilation and cardiopulmonary resuscitation. Candib (2002) postulated that their historical experience of oppression, through slavery and racism, could also contribute to the mistrust of health care providers. These findings need to be understood in the context of an American health system, where access to medical health care resources is not free for all residents, unlike in the UK.

Rao et al. (2008) found in an exploratory study that an Indo-Caribbean sample (N=44) supported the family as decision-makers, but favoured less aggressive interventions (e.g. antibiotics and pain relief) in the case of terminal illness. This appeared to be in keeping with their religious beliefs of Karma. Descriptive studies of the role of religion in relation to autonomy and completion of ADs revealed that between 12% (N=230, Winter et al., 2009) and 43% (N=59; Schickedanz et al., 2009) of people left their health and death up to God. Religion and the belief that 'all must be done to preserve life' was given by 12% as the reason for not having an AD (Mezey et al., 2000). However, people who completed an AD had a higher religiosity than non-completers (DeLuca Havens, 2000). This could be understood by the finding in the Dea Moore and Sherman (1999) qualitative study, that older people (N=20) with a faith experienced less death anxiety and were more comfortable in considering, discussing and planning their own death. Sessanna (2008) explored the role of spirituality in completing ADs with twelve older adults. They expressed concepts like 'connection, contributing, supporting and believing' as important in defining their end-of-life wishes. These attributes did not emphasize autonomy, but reiterated the theme of interconnectedness. When people (N=147) were interviewed who faced a terminal

condition, they often opted for shared decision-making (Sulmasy et al., 2007), reflecting a similar interconnectedness.

The assumption that writing an AD enhances one's sense of autonomy is confounded by the personal, cultural and historical context. Interdependence was a concept voiced by many older adults in the end-of-life decision making process and is perhaps more prevalent than would be expected within a Western value framework. The fact that education with a counselling element had more impact on AD completion rates than education alone might reflect the interconnectedness and dialectic discourse required to facilitate an expression of autonomy in ADs.

Assumption 2: ADs facilitate people's expression of personal values and end-of-life choices.

ADs give people the opportunity to set out the type of care they would like to receive or decline at the end of their life. This assumes that people can appraise possible care options, know what they want at their end of life, and that they notice when their wishes change.

When Porensky and Carpenter (2008) questioned 170 older adults about their knowledge of medical conditions and treatments (health literacy), their accuracy varied between 59 and 94%. Participants knew least about the consequences of the treatments (e.g. most people were in favour of cardiopulmonary resuscitation, but few were aware of the low survival rate of this intervention). Misconceptions and lack of knowledge also undermines the previous assumption that autonomy is based on informed choice. Health education may

well have a role to play in clarifying these medical aspects. However, Campbell et al. (2007) found in their descriptive study (N=118), that people with higher health literacy were less likely to have completed an AD. It is possible that they discussed their wishes with their surrogates, thus assuming that a written AD was not needed or they decided not to proceed as they recognized the complex challenges in writing ADs. ADs can be written by indicating preferences with statements in a pre-designed format. In Cantor's opinion (1998) these statements can be rather general, all encompassing and ill-defined. Underlying certain rather complex statements is the assumption that the patients will know when they are dying (Winter et al., 2010). There are inherent problems with defining the end-of-life interval, and physicians are not trained to, and are often reluctant to, share a prognosis (Winter et al., 2010). Thus, an AD written in advance of a diagnosis or when the person is not aware of the prognosis might not resemble the real end-of-life scenarios and choices.

The format of an AD can also impact on the answers given. Two hundred and two older community residents were asked to: a) complete a standard AD and b) express their wishes for a range of hypothetical health scenarios of varying seriousness regarding disability, prognosis, and treatment options (Winter et al., 2010). Although their answers in the two AD formats showed a significant correlation, the answers to the AD questions only explained 23% of the variance of preferred action in the health scenarios. As the AD question and the health scenarios were asked in the same interview, the apparent difference in views illustrates the difficulties in drawing up a reliable AD. When Sudore et al. (2010) asked 205 people how certain they were of their answer to an unambiguously negative,

hypothetical scenario with poor health status and poor outcome, 45% were uncertain about their decision. Decision uncertainty is understandable when the outcome is irreversible.

When Rosenfeld et al. (2000) conducted qualitative interviews with 21 older people and Hawkins et al. (2005) analysed data from a longitudinal study of 337 older people and their surrogates, they found that older adults were more interested in considering the possible outcome of an intervention, rather than expressing a preference for a particular type of intervention. Rietjens et al. (2005) noticed, in their survey of 1388 adults (age range 20-93), a shift over the life span, from a desire for length of life, to quality of life in older age. This shift could be due to a developmental or cohort effect and a reflection of historical or secular changes. The focus of an AD might need to shift from indicating the level of acceptability of certain interventions, to the quality of life in case of survival, or the desired process of dying. This was supported by the findings from focus groups, in which 11 older people living in long-term care-facilities, their relatives (N=19) and professional carers (N=35) took part (Munn et al., 2008). Translating more general, process-orientated wishes into the level of specificity required for an AD can be problematic.

If people had engaged in some advance care planning, their treatment preferences remained more stable than those who did not. The tendency for change was studied by Ditto et al. (2003) when they interviewed 332 older adults in a two year longitudinal study, with one and two year follow ups, regarding their wishes in health scenarios. They found moderate stability for preferences for life sustaining treatment, with treatment preferences most stable for the most and least serious decisions and for decisions to refuse treatment. This means

that an AD written at a given time could change for about a quarter of people over a period of two years. If preferences change, one would assume that people update their ADs. When Sharman et al. (2008) asked 332 older adults and 329 surrogates to make the same end-of-life treatment decisions some 12 months apart, they also found that 25% had changed their mind. However, older adults had falsely remembered 75% of their original decisions as being the same as their current decisions. Surrogates falsely remembered 86% of older adult decisions as being the same. These findings could not be accounted for by age related cognitive changes, as a similar pattern was found for a group of younger people. These findings reflect a high potential for error if an out-of-date AD is used as guidance for end-of-life decisions. It is unclear how preferences change over even longer periods of time.

The time at which an AD is written was of concern for older adults in the UK (Seymour et al., 2004). They were worried about making the wrong decision at a time of illness, because of their anxieties about being a burden to others. The preference for most participants in survey studies was to consider their options when they were in relative health and not at a time of hospitalization and illness (Molloy et al., 2000; Malcomson & Bisbee, 2007). The American approach, under the Patient Self Determination Act, of asking people during their hospital admissions, is probably not the most desirable for patients. Deciding about end-of-life choices when one is relatively well also has its challenges. When Winter et al. (2009) asked 230 older adults how acceptable life would be in different health scenarios, they used Prospect Theory (Kahneman & Tversky, 1979) to explain that sicker people were more likely to accept poor health prospects than healthier people. When facing death, the option of life even with a poor quality becomes a more attractive option. This is supported by

Decker and Reed (2005), who found that people (N=210), who rated their health as less positive on a questionnaire, wanted more aggressive treatment. There is a need for longitudinal data to see if the Prospect Theory model holds across time. This understanding might well explain a reluctance to express end-of-life wishes in an AD, well in advance of the end-of-life phase, as people might sense that their perspective could alter in light of their changing circumstances.

Some people may never be able to consider their wishes for the end of their life and sign documents that might hasten their death (Bravo et al., 2008). Hamel et al. (2002) and Golden et al. (2009) found that reluctance to discuss one's own mortality was one of the main reasons for not completing AD, although the level of fear of death was the same in both completers *and* non-completers (DeLuca Havens, 2000).

There appears to be a group of people with well-developed and stable ideas about their wishes for their end of life. However, at best, an AD conveys information about the direction of a person's wishes and preferences at a particular moment in time (Mezey et al., 2000; Bravo et al., 2008).

Assumption 3: ADs increase the likelihood that people's wishes will be followed.

People write an AD with the intention of ensuring that their views are considered as part of the decision making process by their family and physicians. The manifestation of the person's autonomy depends on others carrying out their end-of life wishes.

Family and physicians need to be aware of the existence of the AD and have it available to them at the appropriate time and place. Although 95% of older people (N=520) indicated in a survey that they had someone they trusted to make decisions if they were unable to do so, only 49% had talked to that person about their preferences (Hopp, 2000). Winter et al. (2009) noted that ADs may not be available in the medical notes in the setting where the death occurred. Hammes et al. (2010) showed in their retrospective study that, with sustained effort from a coordinated range of services (education materials, medical record policies, assistance from non-physician facilitators and doctors to formulate ADs), 99.4% of people (N= 400) had an up-to-date AD in their medical notes where they were receiving care.

In the Netherlands, 46% had not informed their GP of their preferred place of death (Abarshi et al., 2009). Of those who had told their GP, 88% wanted to die at home or in a care home. The choice of place of death might implicitly convey the type of care wanted at the end of life. Four fifths died in their indicated place of preference. Where there had been transfer of care to other services, the chances of dying in the preferred place were reduced, as the information flow, and the close relationship Dutch patients have with their GP, was disrupted. The impact of relationships comes to the fore again as a factor in the execution of ADs.

As described earlier, an AD can be presented in different formats, which can be vague and not specific or relevant to the presenting health condition or treatments. This lack of correspondence with real life clinical circumstances (Hickman et al., 2010; Winter et al.,

2010) means that ADs can be disregarded by physicians as not applicable to the current decision making process (General Medical Council, 2010). The evidence as to whether ADs are adhered to is patchy. In a major study in the USA involving over 9000 patients in five teaching hospitals, ADs made little or no difference in the care patients received, either before or after an intervention aimed at improving the communication about end-of-life care between patients, their family and physicians (SUPPORT, 1995). Dobbins (2007) found no relationship between the presence of formal or informal ADs and subsequent treatment when she reviewed the medical records of 160 deceased older adults. More recently, Detering et al. (2010) in a randomized control trial and Hammes et al. (2010) in a retrospective study, found the wishes of 86% (N=29) and 99.5% (N=382) of the patients respectively, were respected. These outcomes were achieved after intensive preparatory work had been undertaken, with non-medical facilitators encouraging patients to discuss their beliefs, values and goals with their relatives, doctors discussing the nature of the illness, treatment and prognosis, documenting future choices with the assistance of the treating doctor, appointing surrogates, and systematic filing of all documents. In the control group in Hammes et al.'s study, only 30% (N=27) of people's wishes were adhered to. Intensive work is clearly required to improve communication that aims to understand the person behind the illness in terms of their values and goals in life and death (Rich, 1998). Silveira et al. (2010) reviewed the end-of-life care received by 3746 patients (average age 80) over a six-year period and found that 83% of those who requested limited care, and 97% of those who asked for comfort, received care consistent with these wishes. Fifty percent (N=10) of those requesting all care possible received this, and this was more likely to be aggressive care. Where ADs were not adhered to, it was likely that in 'real-time'

circumstances had changed and surrogates had to adjust and amend their advice. The retrospective nature of this study could have caused a recall and social desirability bias. It is possible that ADs that requested limited intervention or palliative care were more likely to be honoured, as they gave permission to the medical team to restrict their interventions, thus reducing anxiety in the health service of being accused of not intervening. Requesting interventions (which is not possible in the UK) creates a more difficult dilemma for a medical team, if the treatment is deemed futile or too expensive.

The views of medical professionals are likely to influence their considerations regarding the interventions people receive at the end of their life. Schiff et al. (2006) surveyed 842 geriatricians in the UK about their experience with ADs. Although only six percent of geriatricians had helped someone to construct an AD, more than half had cared for patients who had an AD. Thirty-nine percent had changed their treatment because of the AD, with a perceived negative outcome in 14%, while 78% felt that decisions were easier to make. Although most saw advantages to ADs, almost two thirds expressed concerns as well. Concerns were related to the patient changing their mind (85%), completion without understanding (83%), or completion under duress (75%). Fifty-nine percent supported the option under the Mental Capacity Act for advance refusal of treatments². Although almost half supported the appointment of a surrogate, they had concerns about the possible burden on the surrogate, possible conflict of interest, and lack of concurrence of patient and proxy views, and the need for a system that provides a mechanism for resolution where proxy decisions are not considered to be in the best interest of the patient. Ten surgeons in the

USA described in qualitative interviews, the general benefits of ADs in providing a framework to start discussions about end-of-life care, but felt frustrated about the lack of concordance between what was written and intended, and felt conflicted between the battle for a cure and the instructions provided in the AD (Bradley, et al., 2010). Cultural differences have also been noticed, where in more than half of the cases (N=363) examined in a prospective study, doctors in Israel did not discuss end-of-life decisions with patient or family, and another 20% of families were merely informed about the decision (Ganz et al., 2006). The doctors felt that involving families in decisions regarding treatments that were deemed to be futile, would undermine rather than enhance autonomy, as it sent out a mixed message.

Apart from difficulties in the format and specificity of ADs, adherence to AD can be affected by the views of decision makers like physicians. They echoed some of the difficulties with ADs, as presented under previous assumptions. However, their perspectives are crucial in understanding the challenges to adherence to ADs and are an emerging theme in the research. Closer involvement of doctors in discussing and setting up ADs with their patients might well enhance their willingness to execute ADs.

Assumption 4. ADs assist families in their decision-making.

The person can appoint a health care proxy or surrogate to become involved in the end-of-life decision-making and an AD can assist the surrogate in making substituted decisions based on what the person would have wanted had they not been incapacitated. Decisions can be difficult when wishes were not discussed or documented prior to cognitive

incapacity. In the absence of this knowledge, the surrogate, often the doctor, will then need to make best interest judgements³ (Shalowitz et al., 2006; Sulmasy et al., 2007).

Sharing one's wishes formally and informally seems a good way of ensuring that they are known at the end of life. Three quarters of a sample of American, white older adults (N=3838, aged 65) had discussed their wishes mainly with close relations. If people had informal chats with their relatives, they were seven times more likely to have made formal arrangements, be that an AD or the appointment of a surrogate or both (Carr & Khodyakov, 2007). Although older adults wanted to discuss their preferences for end-of-life care, family members especially children, often avoided this or denied the seriousness of the issues, because they were not able to cope with the deterioration or loss of a loved one (Dea Moore & Sherman, 1999; Sansone & Phillips, 1995). Freud explained this as a 'collective denial' (Malcomson & Bisbee, 2009, p.20), where one holds an unconscious belief that we are all immortal because considering the loss of a loved one is unconceivable and unbearable (Freud, 1985).

People clearly had the dilemmas faced by those making the decisions in mind when they completed an AD. Motivations like: 'it can help my family, so they know what I wanted' (89%) or 'not wanting to cause family conflict' (43%) were expressed as reasons for completion (Mezey et al., 2000). Sixty-one percent also thought that it might 'help the doctor decide how to treat the condition'. Hamel et al. (2002) found that reducing the burden on loved ones was the rationale for completing an AD for 16% of 74 respondents.

Those with a close relationship with their confidantes tended to complete more ADs (26% vs. 6%). However, the good quality of a relationship could also be the reason not to complete an AD, as the person was confident that their loved one would make competent decisions for them. The quality of the relationship with others (46 %, N=143) featured also a reason for *not* completing ADs: a poor relationship with family and doctor, not wanting to burden the family, or not having family (Schikedanz et al., 2009). Some people preferred to discuss future care wishes with family rather than health care professionals (Bravo et al., 2008). A longer-term relationship was required to discuss intimate issues of an existentialist nature and these relationships seldom existed with health care providers. The health organisation often did not facilitate these relationships, with regular transfers between doctors and services, and the doctors themselves appeared not open to these types of discussion, either through personal or work restraints (Abarshi et al., 2009; Ditto et al., 2003).

The appointment of a surrogate decision maker implies some level of trust that the surrogate knows what the person wants at the end of their life. When Shalowitz et al. (2006) systematically reviewed the evidence of 16 studies for the accuracy of surrogate decision makers, either assigned by the patient or the state, regarding treatment choices in hypothetical scenarios, they found that decisions were incorrect in one third of cases. Surrogates were better at predicting for current health situations and poorest in scenarios involving stroke and dementia. It could be that the method used in the research of using hypothetical scenarios, underestimated how accurate surrogates can be in real life. Surrogate relationship to the patient was not significantly correlated with predictive

accuracy, but family surrogates tended to predict preferences better than physicians. Prior discussion with the patient about their wishes did not improve surrogates' accuracy. Also, based on the evidence about awareness of people's changes in their wishes (see Assumption 2), surrogate decision makers need to be alerted that a quarter of people change their mind regarding life-sustaining treatment (Ditto et al., 2003) and that surrogates might not realise that this has happened (Sharman et al., 2008). However, the lack of accuracy might not be considered problematic by older people, when in qualitative interviews nine older people (average age 69, range 55-78; C.A. Robinson, personal communication, October 31, 2011) gave their families permission to use their own judgement (Robinson, 2011).

The 'assumed similarity' or 'social projection' phenomenon (Fagerlin et al., 2001), where people have difficulty separating their own attitudes and wishes from their perception of what others might want or desire, was found in surrogates (family and health care professionals). Surrogates (N=361) wanted more treatment than compared with the older person and they over predicted the older persons' desire for treatment. However, as projective predictions had a somewhat higher probability of being correct than counter-projective predictions, projection might be a more reasonable approach to decisions if it is based on a long and intimate relationship, where the person and their values are better known, rather than based on a much shorter patient-health practitioner relationship. The doctor who takes the final decision might be well advised to take note of the views of a close surrogate.

When surrogates (N=50) were asked about their decision-making strategies in real life, two thirds said they relied on conversations they had had with their loved ones, and only 10 % relied on ADs in an attempt to make a substituted decision (Vig et al., 2006). In spite of having had conversations with their loved one, 16% made their decisions based on shared values and experiences, and 28% used their own beliefs and values. Others like family members, clinicians, or spiritual leaders were consulted by 18% of people. Real-life decisions showed the complex decision-making strategies that surrogates employed, and how the surrogates own needs seemed to play a large role. When in doubt, surrogates might take a protective stance, advocating a life saving approach (Bravo et al., 2008), as their own motives influenced the decision-making.

When Detering et al. (2010) questioned family members who had and had not been involved in advanced care planning in the RCT, those who had showed significantly fewer symptoms of PTSD, depression, and anxiety and were more satisfied with the quality of the death. Although physicians (N=206) said in a survey that they were satisfied with the outcome of the decision in four out of five cases, almost a quarter of them felt that making end-of-life decisions caused them a great deal of distress (Torke et al., 2009). This distress seemed to be related to conflict and ineffective communication with the surrogate and a lack of satisfaction with the outcome of the decision making process.

Although the authors of ADs intend to assist surrogates with their decision-making, other factors influence the interpretation of their expressed wishes. The nature and quality of the

existing relationship, as well as motives internal to the surrogate affect the substituted and best interest decisions.

Discussion

Although there are numerous difficulties with the reported studies, not least the bias in the mainly American and white samples and the hypothetical health care scenarios that people were being asked to judge, the literature does challenge the four assumptions that are being put forward in favour of completing ADs.

Challenging the principle of autonomy is more a philosophical debate (Rich, 1998), but the clinical evidence indicates that although valued by most, there are other aspects influencing how one exercises one's autonomy. It may be helpful to think in terms of two types of older adults: the activists who want to have control and be involved in end of life decision-making, and the delegators who hand over control (Kelner, 1995). Although there is no intrinsic value in either position, ADs assume an activist stance towards one's own death. This seemed incongruent with the experience of older adults who voiced their dilemma in being torn between a desire for autonomy and their desire for connectedness with others.

Older adults seemed prepared to connect when they spoke with ease about end-of-life issues to researchers, as shown in the qualitative studies. This connectedness was not always experienced with family and health professionals, who themselves could experience high levels of death anxiety. Family members had their own needs, when considering end-of-life decisions for loved ones, and would benefit from assistance from a multidisciplinary

team to facilitate conversations with their relatives. The (nursing) staff could be of assistance here, as they usually develop an understanding of the person's values and objectives in life through providing the daily care (Mezey et al., 1996; Jezewski et al., 2005). These insights usually develop after a lengthier and in depth relationship, during which end-of-life decisions can be formulated in a way that reflected a connectedness that had developed over time. This also opens up the possibility to include a more holistic approach to end-of-life decisions and ADs, with the emphasis moved away from medical interventions alone, and incorporates other aspects of care that people have indicated as important to them, e.g. psychological, spiritual, emotional and social needs (Detering et al., 2010, Munn et al., 2008).

However, in the opinion of Neimeyer et al. (2004), doctors seemed reluctant to discuss death and dying with their patients. They also had a tendency to more conservative medical decision-making, with more heroic treatment to prolong life. The need to assist health professionals to address their own attitudes and fear has been identified, and training programmes have introduced courses, most of which seem to be obligatory and didactic or self-study (Wass, 2004). Rather than individual study, opportunities should be provided to explore one's attitudes and fears with others, as this will not only model the type of conversations health professionals are meant to have with their patient, but also aid in the psychological processing of personal views, prejudices and fear about end of life. Doctors reported interconnectedness with people at the end of their lives (Bradley et al., 2010; Torke et al., 2009), in as much as personal and professional issues were being triggered, but these remain as yet not fully researched.

Most intervention studies that have attempted to increase the completion rates for ADs have concentrated on educational programmes. Although education does increase knowledge about conditions, procedures and treatment outcomes as well as ADs, it does not enhance connectedness and the relationship with the people that really matter at the end of life.

Clinicians need to develop their communication skills and counselling competencies, which will not only enhance their connections with their patients, but these skills can also help to facilitate communication between the patient and their relatives. In order to do this successfully, staff need to be provided with supervision and debriefing services when they are involved in end-of-life decision making and interventions (British Psychological Society, 2011).

The implicit assumption in most AD studies and legislation is that having an AD in place is the ultimate objective, needs to be replaced by an emphasis on the *process* of discussing end-of-life wishes. Policies need to pay attention to the *process* of involving, facilitating and supporting patients and their families in a meaningful way when making difficult decisions; as well as providing training and guidance to the multidisciplinary team, so that they can aid the process when patients are considering their end-of-life wishes, and possibly compiling an AD (Lemiengre et al., 2007). An AD is the ultimate record of a lengthy, complex and difficult exchange process between those who are living and those who are preparing to die, and not an outcome in and of itself. In summary, ADs often do not deliver what they promise, but in being an option available to people, they facilitate the opportunity to discuss what is important to older people at the end of their life.

Advance Directives

- 1) In England and Wales they are called advance decisions and advance directives in Scotland (General Medical Council, 2010).
- 2) “Advance decision to refuse treatment” means a decision made by a person, after he has reached 18 and when he has capacity to do so, that at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued (Mental Capacity Act 2005, section 24)
- 3) Best interest judgements are made by others, when the person has lost capacity and no AD is available or applicable. ‘Best interest’ is meant to be more objective than substituted judgement, and it considers both the current and future interests of the person who lacks capacity, weighs them up and decides which course of action is, on balance, the best course of action for them (British Psychological Society, 2007)

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**Older people and the euthanasia and assisted suicide debate
in the UK: A Foucauldian exploration of their discourses.**

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Abstract

Debates in the UK regarding legalisation of euthanasia and assisted suicide are ongoing. As the position of those older people who are chronologically closer to death but who do not have a terminal or life threatening condition is seldom heard in this debate, seven such people were interviewed. The interviews were analysed using discourse analysis, drawing on Foucauldian concepts of knowledge, power, subjectification and surveillance. Three main discourses emerged: “confused and conflicted”, “aged death”, and “voiceless in the debate”. Although there was a strong self-determination discourse, conflict arose with other discourses. The medicalisation of dying, which has transformed dying into an illness under medical control and surveillance, was reinforced by other discourses. Alternative discourses of dying outside the ‘medical gaze’ and the possibility of growth and healing emerged. The ‘aged death’ discourse emphasised natural changes in old age, but these were associated with an increased risk of dependence on (professional) others, who seemed to provide poor quality care. Participants reported the challenge of engaging in a debate about euthanasia and assisted suicide. A reluctance and vulnerability was noted in others, even those who are normally seen as powerful in the debate. By using discourse analysis and drawing on Foucauldian concepts, power structures, as reflected in the participants’ language, were revealed which might give a different interpretation to the threat of the ‘slippery slope’. This might be caused less by family members, or even physicians, but by a societal discourse that devalues the ill and old.

Keywords: assisted dying, Foucault, qualitative, healing.

Introduction

Death and dying has changed over the ages, from something that was a common occurrence, happened fast, at a younger age, and at home, to a much slower transition from life to dying, and death at an older age (Kastenbaum, 2000). Advances in medical knowledge and technology have made extended living possible for people, who in the past would have died (The, 2009). However, this increase in medical prowess has turned death from a 'natural' event into an 'illness', where in some conditions the progression and death can be predicted. Thus the experience of a 'terminal illness' has emerged, and with this a separate discipline of palliative care (O'Connor, Davies & Abernethy, 2010), which aims to 'provide holistic care to patients with advanced, progressive conditions, including pain and symptom management as well as psychological, spiritual and social support' (Welsh Assembly Government, 2003, p.4). It is worth noting that there is no reference to dying or death in this statement.

As it is possible for people to be kept alive artificially beyond the point where underlying pathology would have killed them, the moment of death is increasingly likely to be determined by others (Prado, 2003) and to occur in institutions like hospitals, hospices and care homes. In 2003, only 18% of people in the UK died at home, with more than ninety percent of people expected to die in care facilities by 2030 (Gomez & Higgenson, 2008).

With the perceived loss of autonomy over one's dying and death, debates are ongoing in the UK whether euthanasia and assisted suicide (eu/as) should be legalised. Currently in the UK, physicians are permitted to withhold or withdraw treatment, increase treatment of pain

or other symptoms (which takes into account the probability or certainty that this would hasten the end of life), or keep a patient in deep sedation until death without giving nutrition or hydration (Achille & Ogloff, 1997; Löfmark et al., 2008). This can be described as passive euthanasia. The *intentional* termination of life of a competent patient at his or her request, but carried out by someone *other than the patient*, is (active) euthanasia (Gordijn & Janssens, 2000). In assisted suicide, drugs and/or advice are provided to a competent patient, so that he/she can *take their own life* (Wilson et al, 2007). The two latter acts are the ones under consideration in this paper.

Those favouring legalisation argue that eu/as would facilitate self-determination and dignity, and reduce unbearable suffering as experienced by the patient (Dees, Vernooij-Dassen, Dekkers, Van Weel, 2010). However, opponents refer to moral and religious arguments (Badcott & Oduncu, 2010) and the possible risk of abuse (Brock, 2000). Either one or both acts have legal frameworks in the Netherlands (Norwood, 2007), Belgium (Lemiengre et al, 2008), Luxembourg (Oduncu & Sahn, 2010), and in the American states of Oregon (Batavia, 2000), Washington State and Montana (Breitbart, 2010). However, the acceptability of eu/as amongst lay people across Europe and America varies, with higher acceptance among younger cohorts, people from non-manual social classes and higher educational levels, and in countries with a lower religiosity (Caddell & Newton, 1995; Cohen et al., 2006). Professionals, mainly physicians, have lower acceptance of eu/as than the public (Teisseyre, Mullet & Sorum, 2005). MacDonald (1998) noted that eu/as legislation was often more consistent with the opinion of physicians than that of the public.

Borgsteede et al. (2007) suggested that more insight was needed into the views of people who were actually facing the end of their life, like terminally ill and older people. Twenty-eight terminal cancer patients (mean age 61, range 39-79) in Australia presented their arguments in favour of euthanasia as self-evident justifications, with those opposing positioned as morally inferior or ignorant (Eliot & Olver, 2008). However, the views of older people, who are chronologically closer to death, are mainly reported as part of samples of hospitalized or terminally ill people and are rarely heard in their own right. Kastenbaum (2000) postulates that the absence of the voice of older people in this debate could reflect their position in society. However, with an increase in the number of older people in the Western World and with this a 'dying crisis' (Solomon & Noll, 2008), their views need to be considered. In order to assess Kastenbaum's assumption, older people in the UK were interviewed regarding their position in respect to eu/as, society and the eu/as debate, and the related discourses analysed using Foucauldian concepts.

Methodology

A discourse is the narrative of a phenomenon, in this case eu/as, as it has become shaped through culturally shared meanings, social norms and values, personal and group identities, and negotiated interactions (Harper, 2012; Starks & Brown Trinidad, 2007). Discourse analysis investigates the relationship between language and social processes and works on the premise that in language, (hidden) power relations can be revealed (Van der Riet, Higgs, Good, Sneesby, 2009; Graham, 2011).

The process of deciding the time and manner of death is deeply embedded in power dynamics. Ways of talking, thinking and acting regarding eu/as become regulated and institutionalised through the power exercised by implicit rules of the discourses (Jäger & Maier, 2009). Foucault argued that discourses exercise power through a series of mechanisms, and by uncovering these mechanisms insight can be gained as to how thoughts, actions and alternative discourses can evolve. Taking a historical perspective, changes and mutations can occur when knowledge alters, and Foucault has argued that it is knowledge that is crucial in power relationships (Dreyfus & Rabinow, 1983; Gutting, 2005). Knowledge classifies and divides people and in the process ‘objects’, ‘subjects’ and ‘experts’ are created. Through these positions, power is practised in relationships and manifests itself in actions (Pickard, 2009). Foucault suggested that the physical body has become the place where these powers become manifest, in linking local social practices with large-scale organisations of power, such as hospitals (Dreyfus & Rabinow, 1983; Pickard, 2009).

The historical change in illness, dying and death previously described, has resulted in the person’s experience becoming the physician’s object of knowledge and (s)he uses specialized and exclusive language of diagnosis and treatment when talking about the ‘object’ (O’Connor, et al., 2010). To conform to this medical discourse and the related behavioural norms, people turn themselves into ‘patients’, hence becoming the ‘subject’ of the discourse. The process of internalising a discourse is described by Foucault as ‘subjectification’ (Prado, 2003; Pickard, 2009).

Thus, discourses around dying and death have become biomedical and disease orientated, removed from the 'subject', impersonal and disempowering (Nicolson, 2009). The state-licensed authority of a physician oversees treatment and monitors the 'objects' in institutions (Ost, 2010). This is the most economical way to provide health care, through which patients can easily remain under a constant 'medical gaze' and surveillance (Dreyfus & Rabinow, 1983; Gutting, 2005; Kaufman & Morgan, 2005). As the 'subjects' experience the potential of constant monitoring, they begin to monitor themselves, thus exercising self-surveillance. Foucault considered this a powerful control mechanism.

The emerging discourses related to the position of older people regarding eu/as, the position of older people in society, and their engagement in the eu/as debate will be reviewed for evidence of the Foucauldian concepts of knowledge, power, subjectification and surveillance. A Foucauldian perspective might make the hitherto quiet voice of the older person heard and reveal how societal discourses about eu/as are impacting on older people's appreciation of their end-of-life choices.

Sampling

After ethical approval was obtained from the School of Psychology Ethics Committee at Bangor University, recruitment took place via advertising (pp. 172) through local organisations for older people, and opportunistic recruitment. Prospective participants received an information sheet (pp. 174) setting out the focus and nature of the study, with the invitation to contact the first author for further information. Interested participants were

contacted by phone or e-mail, and, if they agreed, formal written consent to take part was obtained (pp. 180).

Participants

Seven white British people, all over 65 years, who at time of interview did not have a known terminal condition or a mental health problem, participated in the study. Five participants knew each other from a discussion group about dignity and dying, and two participants of the group were partners. Demographic data were recorded i.e. gender, age, profession, health, faith or spiritual life and recent bereavements (Appendix 2.1; Table 1).

Table 1. Demographic details of participants⁴.

Participant⁵	Gender	Age	Marital status	Profession	Health	Spiritual life	Bereavements
Beth ∞	Female	78	Widow	Teacher	Stroke/ epilepsy	None	Husband, 1 year ago
Ellen	Female	67	Divorced	Administrative worker	Past: Cancer	None	None recent
Andy *∞	Male	67	Divorced/ Cohabiting	Government worker	Arrhythmia	None	Mother, 4 years ago
Liz * ∞	Female	67	Divorced/ Cohabiting	Care assistant	Fit	Church of England	Mother in law, 4 years ago
Iris	Female	67	Married	Clinical Health Professional	Good Past: Cancer	Christian	Mother, 2 years ago
Violet ∞	Female	70	Divorced/ Cohabiting	Teacher	Excellent	Quaker	Not recently, mother 10 years ago
Ester ∞	Female	72	Divorced	Teacher	Asthma, allergies	Not sure	Mother 10 years ago, Father 30 years ago

* Partners

∞ Members of Dignity and Dying group

⁴ All participants' accounts are presented under a pseudonym and any identifying details have been anonymised or generalised, in order to preserve confidentiality.

Interviews

The first author conducted all interviews, either in the participant's home or at the University. As the first research participant knew that the interviewer originated from the Netherlands where eu/as is legislated, this information was disclosed to all participants. An outline schedule (Appendix 2.2) was developed based on eu/as literature as well as the Foucauldian concepts to be considered in the analysis. As Foucault considered knowledge as a prerequisite for power, the interview schedule started with asking the participants to describe the nature of the acts of eu/as (externalizing; Potter & Hepburn, 2005). The definitions offered were used to guide the rest of the interview, even if they did not conform to the legal definitions of eu/as. Alerting the participants to the legal definition would not only have artificially changed the discourses available to the participant, but the interviewer's power position would have been accentuated. To ascertain the historical context (described as genealogy by Foucault; Gutting, 2005) in which the participants' discourses around eu/as had emerged, they were asked to reflect on the origins of their views on eu/as and how they had arrived at their current position regarding eu/as (personalising/ explicating). Further questioning regarding circumstances under which the participant would consider eu/as as well as any actions they would consider undertaking (specifying), would attempt to access discourses reflecting the participants' object and subject position, and also any possible discourse regarding any surveillance they might experience. Further prompting occurred in an explorative manner that allowed for the flow of the interview. Interviews lasted between 40 and 65 minutes. The transcripts of the first 2 interviews were reviewed for the appropriateness of the interview schedule, the explorations undertaken and the richness of the data. Any explorations undertaken in the

interview would require ongoing self-monitoring on the part of the interviewer, to ensure that the interviewee's discourses were not interrupted and disrupted by the positioning of the interviewer. The interview schedule was amended to include participants' reflections about other people's considerations regarding eu/as, and they were prompted for any other comments not previously raised.

Method

Whilst there is no widely agreed method for Foucauldian discourse analysis, the procedures set out by Georgaca and Avdi (2011) were carried out. Interviews were transcribed by the first author and checked for accuracy. Vocal tones, pauses and hesitations were included subsequently⁶. After listening to the interviews and rereading the transcripts, emerging themes were identified and underlying discourses defined in relation to the participants' position regarding eu/as, the position of older people in society and in the eu/as debate, whilst monitoring for possible differences, omissions and alternative interpretations. All identified discourses, noted omissions and alternative interpretations cannot be considered exhaustive nor comprehensive, and will reflect and be sensitive to the limitations of the authors' knowledge and positioning in the discourse. The use of language and management of interactions were analysed. Evidence for expressions of the Foucauldian concepts of knowledge, power, subjectification and surveillance was sought, as well as evidence for social and institutional practices which might maintain discourses. (Appendix 2.3: Sample interview transcript and analysis).

First author's declaration.

The first author originates from and trained as a social gerontologist in the Netherlands, where eu/as is legislated. This background combined with witnessing ongoing debates in the UK, and, as a clinical psychologist, facilitating older people's end-of-life challenges, created the research questions. The research methodology reflects the author's emancipatory and critical stance, that alternative discourses about ageing and dying might be able to emerge when discourses about older people and dying are made visible, power relationships identified, and the impact of societal discourses on older individuals' perceived options at the end of life explored.

Interpretations

As discourse analysis does not aim to reveal the truth but present an alternative perspective which is contingent upon the author's and the reader's influencing discourses (Graham, 2011), the findings are presented as interpretations.

Three main discourses emerging under each of the research questions – “confused and conflicted”, “aged death”, and “voiceless” - will be presented alongside further discourse strands, whilst attempting to illustrate the Foucauldian concepts of knowledge, power, subjectification and surveillance, where appropriate. (Appendix 2.4: further examples illustrating the discourses).

Confused and conflicted

The participants' position regarding eu/as revealed an overarching discourse of confusion and conflict. The confusion started as they struggled to describe the difference between euthanasia and assisted suicide. Their apparent lack of knowledge about the nature of the two acts was expressed by checking with the interviewer.

Violet: Euthanasia I I understand and I would like to be corrected if you think I'm wrong, or if you know that I'm wrong.⁵

With knowledge and related expert language identified by Foucault as a prerequisite to exerting power (Van Dijk, 2009), the participants were disadvantaged.

The lack of clarity regarding the exact nature of the acts seemed to have made participants hesitant and anxious regarding the responsibilities and practicalities of undertaking eu/as, and they confused eu/as with passive euthanasia and options available in Advance Decisions, the only way that people in the UK can legally express their end-of-life wishes (Department of Constitutional Affairs, 2007).

Liz: 'I suppose it, hh I wouldn't want to be, well I say I wouldn't want to be aware, but I would make the decision to do it so I eh (...) I hadn't really thought that I was conscious really, I just thought that I I I had this and they would produce it and that would be it and just go (laughs).

Although their knowledge was patchy, they revealed three discourse strands regarding eu/as: self-determination, family involvement and medicalisation of dying.

⁵ Bold: said with emphasis, louder voice. Underscore: said softer, quieter, under breath. (.) Noticeable breathing space, (..) 3-5 seconds pause, (...) more than 5 second pause. (... ..) Text removed for readability

1) A ‘self determination’ discourse expressed a desire for agency, referring to a right to autonomy, choice, capacity and voluntary decision-making.

Ellen: It’s about what you want, not what anybody else wants.

Violet: The central person in this has made a clear choice to have their life end at the moment of their choosing not at the moment of just ordinary life span or a medical person or a religious person.

Participants emphasized that self-determination also meant that other people will have different wishes for their end-of-life rather than eu/as.

Participants expressed a sense of self-knowledge, in knowing when they wanted their life to end; they are the expert in their own wishes and needs.

Liz: I would, I don’t like the idea of him giving you tablets before you are ready, eh so eh

CL: You need to be ready for it?

Liz: Yes, yeah

CL: How, have you got any sense how you would know when you were ready?

Liz: (...) Well, I would eh (...) well I would know for sure I would know when was ready

Andy saw suicide as a way of expressing self-determination, while others associated suicide with an act of irrationality and mental illness (Brock, 2000).

2) Although a self-determination discourse was voiced, end of life decisions were seen as a family affair. It was acknowledged that asking for involvement and agreement from relatives in end-of-life choices could elicit strong feelings (e.g. guilt). There was little reference to emotions, which might be triggered when a non-eu/as death occurred. This discourse can be seen as inviting surveillance over actions, and desire for approval.

However, some people (‘disabled’ (Beth), ‘little old ladies’ (Violet)) were considered as more vulnerable to being coerced by ‘rapacious’ (Ester) relatives into eu/as (Odunco &

Sahm, 2010). None of the participants acknowledged knowing or having ‘*rapacious*’ relatives. Although the vulnerability of ‘others’ was acknowledged, some participants clearly removed themselves from the ‘vulnerable, abuse’ discourse, stating they could not speak on behalf of ‘older’ or ‘disabled’ people. Moreover, female participants did not identify themselves as ‘little old ladies’, although Beth did refer to ‘widows’. The reference to women may relate to a societal discourse, which sees women as weaker, especially with the added diminutive reference of ‘little’.

3) The self-determination discourse was tempered when participants spoke about the medicalisation of dying (Ost, 2010), where ‘somebody’ decided on the utility of the ‘patient’ who was diagnosed with a terminal illness or a progressive condition: *Iris*: ‘*they don’t need to live any longer*’. The expert judgement of the physicians was accepted as accurate and complied with.

Ellen: And I’d rather somebody said to me ‘right you can, you, you can’t’ you’re not, you’re not gonna get any better, and I think now is the time for you to go.’ And I would say ‘yeh’

However, ‘others’ might not allow eu/as, as ‘*they want to save you (Beth)*’ and the ‘*medics have, we’ve gotta keep this people, this person, alive*’ (*Andy*). The impersonal reference to ‘they’ in *Iris* and *Ellen*’s comments that ‘somebody think[s] now is the time for you to go’, implies an object and subject status, where the expert exerts their power through their knowledge and judgement and ‘they’ (e.g. *Ellen*) acquiesce as subjects. From the context it appeared that ‘they’ and ‘somebody’ were referring to physicians. The anonymous deciding ‘other’, concurs with an ever-present ‘surveillance’.

The medicalisation of dying was further endorsed in several other discourse strands. As most had witnessed others die, they had observed suffering that they considered unbearable for the person and for them as bystanders (Chapple, Ziebland, McPherson, & Herxheimer, 2006). Although physical suffering especially pain was mentioned, it was the anguish of the inevitability of death and the impact this had on others that seemed unbearable.

*Liz: I don't want to **linggger**, I don't want to **linggger**, ehm you know drifting in and out of consciousness and every body stood around your bed and oeff.*

Avoiding this suffering for themselves and protecting their families from having to endure the same distress was key. The 'passive gaze' of being watched as 'subjects', expressed an absence of agency.

Liz: Her mind was active and her body just decayed about her. And there was no way I'd want to go through that what she did or for her, my children neither. Cause eh, you know, every day you went, she wanted to die'. I mean that's awful isn't it, you know. I mean there are times really, if she had asked me I might have put a pillow over her head myself, really cause I just felt so sorry for her. But I didn't (laughs).

They invited the 'medical gaze' i.e. the physicians, to apply their knowledge and power to facilitate a hastened death.

Ellen: I think if they'd had assisted her, (.) it would have been better for her. Not so much for her, it would have been me, cos watching people die is awful, awful. And I wouldn't wa, like want them t'watch my mother, watch me die as I watched my mother die.

Physicians were also accepted to assess decision-making capacity regarding end-of-life choices, further endorsing their expert surveillance role. Their assessment was seen as benevolent and beneficial to ensure that the person was making an informed choice and not taking a 'suicide' pill by mistake on an 'off day'. The 'subjects' mistrusted and doubted

self-knowledge and deferred to and trusted physicians' judgement. This contrasted with the self-determination discourse where participants had stated they '*kn[e]w when [they were] ready to die*'.

Beth: I would trust the doctor. (.) I would trust the doctor, and if he, he chose to, as it were, put up the medication, even though there was a risk of death, but there was also (..) the fact that the pain would be relieved. I would risk, I would, you know, support the doctor to do that. Because I think, by and large most doctors are very caring people. [coughs] You get a few rogues, don't you.

These 'rogues' were perceived to make mistakes such as misdiagnosing life threatening conditions as well as 'overtreatment' in the face of impending death. Not only was their expert knowledge about the 'object' and 'subject' questioned, it also created an abuse discourse in which it was not the 'rapacious family', but the physicians whose actions were seen as abusive.

Ester: I was furious because (name doctor) then put a foodplug, a food tube up her nose the night before she died.

Although participants expressed strong emotions when challenging the physicians' power, the language remained mild and descriptive. There appeared to be an implicit discourse where no evil is spoken of doctors, as Beth states, most doctors are *trustworthy* and *caring* people. Nobody mentioned other health professionals who were convicted of killing their patients, like Shipman (Houghton, 2004) who seemed to operate under apparent limited surveillance of his practice.

When asked for clarification on the range of discourses, participants expressed irritation and frustration with the interviewer for drawing attention to their confusion and conflicting ideas, and they re-emphasised the self-determination discourse.

Ester: I don't care what you call it, you can call it outer Mongolia Be Go To, but what I do want is to be able to end my life at a time when I want.

Andy: This is just playing with words, isn't? Ehmm. (...).

Although the self-determination appeared the main motivation to consider eu/as, conflict arose through discourses of family involvement and the medicalisation of dying.

Participants felt few options were available apart from passive compliance with the current situation. Advance Decisions were described as confusing and cumbersome in organising, whilst others acknowledged their limitations. Some had considered the possibility of enlisting the help of Dignitas⁶, but the risk and trauma of prosecution, difficulties with practical arrangements, financial costs and the emotional strain or guilt, were considered major obstacles. Apart from the legal consequences, the anticipated social disapproval by anonymous 'others' influenced choice. This could be seen as an internalised form of surveillance, as the threat of being judged constrained people (Gutting, 2005).

Beth: And you wouldn't have the eh (...) social disapproval either if you could do it in this country if it was legal.

CL: Who would disapprove?

Beth: (...) I have no idea but I think a lot of people would. People that you make contact with. (..)

⁶ Bold: said with emphasis, louder voice. Underscore: said softer, quieter, under breath. (.) Noticeable breathing space, (...) 3-5 seconds pause, (...) more than 5 second pause. (... ..) Text removed for readability

Legalisation of eu/as similar to the Dutch legislation was seen as the only way to ensure that people could express control over their end-of-life choices, although Iris expressed reservations that eu/as did not automatically mean the dying would be 'good'. It was only Andy who queried the impact carrying out eu/as could have on the physician. This refers to the physicians' position as 'subjects under surveillance', who need to adhere to the law and the professional code of conduct (and related discourses), which regulates their medical behaviours.

Andy: They're in a conflict, I can see you know, they've a professional, Hippocratic Oath and their whole life has been spent training for and keeping people alive, and then somebody comes along and says 'when I reach point A, don't do anything to help me'. And it's a conflict for them. They got the problem just as much as we have.

Non-compliance with the medicalisation of dying and alternatives to dying under the 'medical gaze' did emerge: dying at home or without further medical interventions. These dying processes were described as more peaceful and gentle, where growth, connection and healing into death could occur. An alternative discourse of care and nurturing emerged.

Ester: If you got a family and supportive, like the neighbours here, he died in his bed with his family around them and he's being going down hill very gently for the last three or four months, looking frailer every day. That's an ideal end.

Violet: This person decided not to go for treatment cause he was had a medical background and just what was the value of that..... he would say ehm (..) that it was it was an interesting time, this process of dying, and he was rather enjoying it and then he sort of said 'I don't think anybody would believe me'.

However, this deviation could be rewarded with personal and kinship fulfilment during one's dying days. Knowledge and support from the family seemed to be required to achieve this. In not adhering to a dominant discourse, the possibility of an 'unbelievable' discourse

emerged where people can grow, heal and be nurtured into death, in a private, family endeavour.

Iris: Healing is about helping that person to be at peace with themselves in whatever way.

An aged death

The discourse reflecting the position of older people in society emerged as living an ageing life with limitations (Seale, 2000). Although participants preferred a sudden and rapid death, they appreciated that it was more likely that their death was going to be preceded by an ageing process involving inevitable changes to their bodies (stroke, arthritis) and minds (dementia). This prospect was accepted as the natural order, unlike the ‘undeserved death’ of a child (O’Connor, 2009). This acceptance appeared congruent with the metaphors used to describe these changes: poetic (a journey), playful (a race) and philosophical (a natural cycle).

Andy: I am 67 now. How long am I supposed to go on for? Well (.) It’s like (.) going into a race, isn’t? You know you’re gonna reach the, the, the tape at the end sometime and so you prepare for what you got to do at the last bit, it’s just a fact of life.

Violet: Maybe connected with my name, that the flowers come into it and they do their podding and they do their seeding. Done that, so no, compost is the next good stage.

Although there was an acceptance of ageing and end-of-life (e.g. Andy), the possibility of being alive but not having a life, because of failing physical and mental health, appeared to cause anxieties and apprehension in its own right.

Ester: Not to go through the descending awful time of life when you are lose all your independence. I think that’s what I’m most afraid of and many other people I’ve spoken to.

Andy: I mean the incontinence, double incontinence doesn't exactly appeal. Ehm, not being able to feed myself and be, you know, reasonably coherent, tidy and socially (chuckle) acceptable is eh, doesn't appeal to me at all. I've always been a fairly independent sort of person and eh, I don't want to suddenly find because I'm inna incapacitated for no good reason of my own, that I have to put up with it.

When asked to define independence, participants usually referred to doing things for themselves, although they reflected that they might accept lower levels of independence in the future (Winter, Moss, & Hoffman, 2009). Dependence was seen as a loss of control and others exercising their power (See next extracts from Ester and Andy).

With ageing, the discourse changed from valuing independence to having little choice but to tolerate being dependent on others, something which requires grace, being open to kindness, and a willingness to trust the strength and compassion of others (Street & Kissane, 2001). But, due to changes in social structures (divorce, economic migration, no or few children, working women; Seale, 2000), carers were likely to be professional strangers with whom it might be harder to have this sort of relationship. Foucault would see the loss of family support mechanisms as a historical context and a reflection of changes in societal structures and thus power relations.

Ester: The people in Britain mostly have had to move away to find jobs, Mrs Thatcher told us to do that.

The care they envisaged they would require was not described as specialist, expert (palliative) care, but regular care in facilities for older people. The position of dependence seemed devalued (Prado, 2003), not only by the person receiving the care but also by those providing care. The care received was seen as an expression of an underlying perception

that older people were not human (*robot*), not worthy of care and isolated from human contact.

Ester: I don't have to suffer the indignities of being in a nursing home, sat around a wall, staring at the paint drying, as most people do. Fed probably, possibly, hopefully kept clean, possibly, hopefully, but with no stimulation or possibly not able to take stimulation, just be a robot.

Andy: It means that somebody else has got to do my washing for me and somebody else won't clean my teeth for me, they don't.

Physical suffering itself appeared of less concern, than the shame of a disintegrating body (Street & Kissane, 2001) and the psychological anguish about being dependent, dehumanised and disconnected. The older person appeared invisible to the world around them, as if the 'medical gaze' was looking away and the surveillance of them and the services provided was removed. And yet, quiet tolerance of their dependence, compliance and possibly gratitude for receiving food and shelter seemed to be expected from the 'subjects'.

With the prospect of being weakened, worn out, debilitated and dependent, and facing a 'decrepit death' (O'Connor, 2009), eu/as was considered a possible way of regaining a sense of control and independence. The self-determination discourse resurfaced not as an approach, but as an avoidant response (Elliot, Gable & Mapes, 2006)

*Beth: I thought if I get to the stage when I can't look after myself, cause nobody look after me, I'd have to go straight into (name of nursing home) and I **definitely** would not want that. (My husband) did not want it either. (.) And I would just **hate** to think I'd have to do that and my, my it would give me a **huge** amount of comfort to think (.) if I decide I've had enough and I want to die, to die at home with the people that I'd wanted with me and just say 'right, now is the time, I want to go' and that'd give me **huge** relief.*

Participants reflected on the historical place of death in society and how relatives from a previous generation seemed to have accepted their ageing, the care they received and their deaths. Even when they reported distress in their older relatives, none had requested to hasten death. Eu/as were not end-of-life options at the time, and most participants felt that eu/as would not have been acceptable to them. However, being from later cohorts, the participants had become accustomed to exerting control over their lives and being independent (e.g. birth control) and wished to continue to doing so. Andy also referred to a possible developmental phase:

Andy: The next generation down in their sort of forties, they don't wanna know. (.) They don't want us to talk about it, I don't think, although they don't say that. But it is our problem, not theirs, but of course they have to (.) be the following generation, who gotta follow through with it.

Ellen: You can die at any age, can't you, lets face it.

Foucault referred to this change in perception as the genealogy of discourses, contextualised in historical developments (Gutting, 2005).

Having to depend on health and social services was seen as using resources that were more valuable to 'others' (younger people). Andy saw '*no point in wasting money on somebody, who is to all intents and purposes dead, to keep em alive*'. Beth commented that she had cost the health service '*goodness knows what*' and that since becoming a widow, she had considered moving to a smaller house, partly for convenience, but also she felt that her '*house is for a family, really (...)*'. Ester felt that '*the best of it all, goes to the young not to the old*'. Where 'others' assessed the utility of a person (*they don't need to live any longer, no point wasting money*), the participants appeared to have internalised this discourse and

in self-surveillance, reviewed their own utility and value, as a member of society. A discourse of productivity and usefulness might well preclude access to scarce resources, for those not considered valued members of a community. The historical discourse of the contribution of wisdom in old age was unexpectedly absent in all interviews, and perhaps reflects a change in the status of older people.

Voiceless in the debate

With inaccurate knowledge about the nature of eu/as, the positions of the participants as equal powerful partners in a debate, was already jeopardized. However, other internal and external barriers hindered further engagement.

Although participants were willing to set out their position in the eu/as debate during the interviews, an (unconscious societal) discomfort with death through eu/as was reflected in the euphemisms used to describe eu/as: *'help people on their way'*, *'put to sleep'* and as seen before through metaphors used when describing an aged death, where 'dying' and 'death' were not mentioned either.

Participants were protective towards others, sensing their vulnerability (*Beth: [a friend] found it just too much to take part in [a discussion group]*), especially their children's (Leichtentritt & Rettig, 2000).

Discussions about death wishes appeared to be brief or postponed, thus maintaining an uncomfortable silence. Even when facing real end-of-life decisions, Beth fell silent, waiting for her husband to re-affirm his (earlier) wishes.

CL: With your husband becoming unwell, how did you then talk about your life membership [of Dignity and Dying]?

Beth: Well, I didn't talk about, I didn't introduce the subject cause I thought if he wants to talk about it, he'll talk about it. And I decided that I would wait for him to broach the subject and he didn't. (.) He didn't at all.

The barriers in others were perceived as their denial or fear of death (Eliot & Olver, 2008), or due to strongly held beliefs. This manifested itself in one participant ending a conversation about taking part in the research, defending herself against the 'little old ladies' discourse and emphasizing the self-determination discourse. This incident supports the earlier discourse of vulnerable women.

Ellen: 'You're too vulnerable' he said, 'you shouldn't be ask, answering questions like this, you're a vulnerable person', because he thinks I'm gonna sign up, from, to put my death..... In the end I had to turn around and say t'him 'it really 's none of your business'.

It is worth noting that although participants knew others who held strong views opposing eu/as, they reported that none of them were willing to be interviewed. Although supportive responses were reported from family, friends and physicians, others who were seen to be influential in the eu/as debate had curtailed discussions about end-of-life options. A MP quoted 'principles' and a doctor referred to the Hippocratic oath. They both adhered to 'guidance' from their organisations, exercising their institutional power.

Iris: I remember (chuckles) asking a local GP 'if my mother wants to make a living will, how would she do it?' and he was very taken a back and was like 'No, I am here to preserve life'.

Violet: When I wrote to [MP] and said there's an EDM, Early Day Motion, that that he I wished he would support, he said 'I'm totally opposed to this on principle. Therefore I will not support you in your principle'.

CL: Hmm, did he explain why?

Violet: No, no, that's as far as it went, he said that was, we don't talk deeply because we know that we disagree on everything, but I do keep writing to him (laughs).

Both participants laughed, as if they sensed other reasons for non-engagement, possibly the person's own vulnerabilities or powerlessness in having to 'tow the party line'.

It is worth noting that in the current abuse discourse expressed in the 'slippery slope' argument (Oduco & Sahm, 2010), vulnerability is located in those who are ill, disabled and elderly, not in younger children, contemporaries or those who are normally seen to hold 'power'. The legislation protects the 'vulnerable' rather than controls the 'abusers', a reflection of how power is exercised.

In spite of the challenges of engaging others in a debate, some participants exercised their power by joining 'a small group', which Beth had started, where they were able to create their own discourse, including one similar to Eliot and Olver's participants (2008) about 'others, who were not facing up to reality'.

Andy: It annoys me when I see intelligent, more intelligent people than I am, eh, more capable than I am, eh not wanting to talk about it. For God sake, (sigh, chuckle) it's ridiculous.

Beth had found a non-verbal way of expressing her views by wearing a 'small' Dignity and Dying badge: "even though I've worn [the badge] for several years now, there's only one person ever asked me about it". The media and especially the film 'A short stay in

Switzerland⁷, were seen as helping to assert the groups' views and desensitize others to the eu/as debate. The role of the media fell outside the remit of this paper, but appeared to play a powerful role in defining and reinforcing particular discourses (Hausman, 2004).

Apart from not finding willing debating partners, different rules appeared to apply to the actual debate around eu/as, which made participants sound very frustrated. Those *not* in favour of eu/as were seen as silencing discussion through their strong emotional reactions, one-liner statements, or by deferring to principles, without further explanation. Those in favour of eu/as seemed to be challenged to be *more* rational, logical and moral. Arguments appeared to be examined on a ranking system of comparisons, which then controlled the debate (Gutting, 2005).

Violet: there're a lot of humanist, non non organised religion but with very clear and moral motives and grounding and those people are being totally ignored, negated. I think that I feel very negated that as a thinking person I can make a choice and I find other people can still say: your choice is wrong, you're not allowed to do this.

Participants argued that they were competent and rational, clearly drawing on the self-determination discourse, but they also showed their consideration for differences in opinion, something they felt those opposing did not exhibit (Eliot & Olver, 2008).

Violet: That I find difficult, because it's somebody else's view, I don't mind it for them but I do mind it for me cause it's not my view. But but that that could be a power, a blocking power in in the opposite direction.

⁷ This film portrays the real life story of Dr Ann Turner, a British woman with Progressive Supra-nuclear Palsy going to Dignitas with her children, to be assisted in her suicide.

The required rationality seemed to resemble ‘object(ive)’, expert knowledge, rather than the ‘voiceless, subject(ive), lay’ experience of the dying person. The intensity of emotions, reflected in angry repetitions and strong language noted in several interviews, seemed in contrast with the rationality and detachment required in the debate. Despite attempts to approach the eu/as debate rationally, aspects of participants’ emotions and experiences played a role and were expressed vividly, and could not be stopped from mingling with the rational. Dying might not be the time when one can rely solely on rationality as it is *‘difficult to think the unthinkable if we don’t know what it is (Violet laughs)’*.

Discussion

Seven older people referred to multiple and conflicting discourses when talking about eu/as as possible end-of-life options and it left them struggling to find a discourse that was coherent enough to assist them in their positioning. The lack of fluency and numerous hesitations noted in several interviews might have reflected their search for a powerful ‘alternative’ discourse. Their patchy knowledge about the exact nature of eu/as would reduce their power in a debate.

The participants represented a group of seven self selected, white, middle class and mostly educated participants, who were all to a certain degree in favour of eu/as. Although this could be advantageous in establishing discourses pertinent for this group, the group was not a representative sample. People, from different backgrounds and who were more ambivalent or not in favour of eu/as, are likely to draw on other discourses in which different power relationships will be expressed. The reluctance noted by the participants, of

people not in favour of eu/as to engage in a debate, might have contributed to people not in favour of eu/as not volunteering to take part in this study. Hence their voices and discourses, including a possible discourse regarding non-engagement in an eu/as debate, are absent.

As discourse analysis is interested in the multivoicedness in the discourses, it is not only those opposing eu/as that have not been heard, but there will be several other groups of people, who are likely to have other discourses regarding aging, death and eu/as. A range of demographic factors is likely to have impacted on the discourses. All participants were white, educated and British and will have reflected Western discourses about ageing, dying and eu/as. These will probably differ from discourses of people who have a different level of education, religious background, race and culture, where independence is valued differently, older people hold a different position in society, and care is organised differently (Candib, 2002). The majority of the participants were 'young-old' and female. Old-old people might have different discourses than young-old people, partly as a result of their developmental phase or their cohort. There appeared to be gender stereotyping with men portrayed as heads of families, rational and detached, while women seen as weaker. Older women were stereotyped as 'little old ladies' and widow. Andy, the only man, did raise different aspects to discourses, which were not mentioned by the women.

Within the sample studied, the five people who were members of a dignity and dying discussion group, could have developed their own homogenous group discourses which might have influenced the overall discourse and thus the interpretation. However, not only were alternative and different (multivoicedness) discourses noted amongst the group

members, it was also possible to find quotes from the other participants, who were not part of the dignity and dying group, which supported the identified discourses.

The fact that older people felt the need to meet and discuss issues of dying and dignity might also illustrate the absence of a current discourse for older people that felt comfortable and supportive of a position in favour of eu/as. It is worth noting that despite their interest in the topic, several group members struggled to describe the nature of the acts of eu/as.

While participants expressed a self-determination discourse, they had few other discourses available that provided them with agency over their end-of-life decisions. As soon as a person had been identified and labelled as a patient with a terminal or degenerative condition, they became the ‘object’ of the ‘medical gaze’ (Graham, 2011; Nicolson, 2009).

Participants appeared to comply with the position of ‘patient’ and transferred their agency to ‘others’ (physicians and family), who were deemed to have greater knowledge. The medicalisation of dying was further reinforced by inviting a hastened death when the onlooker found ‘the watching’ difficult and through approval of the assessment of one’s mental capacity. This compliance undermined the self-determination discourse. There was some minor dissent when the physicians’ knowledge about the ‘object’ and ‘subject’ was challenged. However, dying outside the ‘medical gaze’, promised an ‘*unbelievable*’ discourse, where dying could mean growth, nurture and healing. Erikson described the possibility of achieving a balance between integrity and despair in old age, in his Theory of Psychosocial Development (Erikson, Erikson & Kivnick, 1986), where wisdom might be obtained. Not only are the words growth, nurture and healing absent in the recent End of life Care Strategy (Department of Health, 2011) and the Strategic Direction for Palliative

Care Services in Wales (Welsh Assembly Government, 2003), none of the participants mentioned palliative care. Apart from not being familiar with the service, it could be that palliative care was seen as part of the ‘medicalisation of dying’ (O’Connor, 2010).

Clinicians need to be alert to prominent discourses in their services about dying and death in old age and the impact these could have on wellbeing and people’s ability to explore end-of-life options. Foucault said that when people think they operate out of self-determination: ‘powers are at play that the person will not be aware of’ (Gutting, 2005, p. 33).

A more striking discourse was one of ageing and an aged death, which participants accepted as a natural and expected endpoint of a long-lived life. For society however, death in old age seems to have become predictable and ordinary and not requiring special attention or resources (O’Connor, 2009). This discourse might be expressed in less than adequate quality of care provided to older and dying people, as health-care professionals come to see older people as unworthy of ultimately futile time-consuming treatment (Van der Riet et al., 2009). Health services in England and Wales were recently urged to improve the care for older people by the Parliamentary and Health Service Ombudsman (2011) and the Older People’s Commissioner for Wales (2011). The request to look after older, ill people better, seems in conflict with sentiments expressed by other government departments who refer to the ‘burden of ageing’ when expressing concerns over the affordability of pensions and care for older people (Dilcott Commission, 2011) and the Welsh Assembly Government National Service Framework for older people (2006) that wants to ‘challenge dependency’.

These societal discourses convey conflicting views about the value of older people, and appear to have been (unconsciously) internalised (Hausman, 2004) by participants, when they consider eu/as as a way of avoiding growing old, being recipients of poor quality care and becoming a burden to others and society. Foucault argued that when people internalize discourses and behave accordingly, this is the most economical and efficient way of control. Self-surveillance leads to self-regulated abstention from costly health care at the end of life and choosing one's moment of death would be an effective way to control rising health and care costs (Prado, 2003). The danger of the slippery slope might not lie in 'rapacious' relatives, nor 'rogue' physicians, but in the pervasive, negative societal discourse that has developed regarding old people and the silence around dying an aged death. But with no other acceptable discourses available and no imminent change in the law expected, the medicalisation of dying discourse is likely to remain a powerful discourse where end-of-life care decisions are concerned.

A stronger ageing discourse might not provide immediate agency, but the distinction between illness and ageing might move death and dying from the control of an elite group, i.e. physicians, to a constantly growing number of older people who might be able to shape this ageing discourse. Kuypers and Bengtson postulated in 1973 that older people needed their own reference group which sets norms, role models and standards, rather than depending on societal external labeling which tends to see older people as obsolete, incompetent and negative. However, when Pratt (1995) reviewed the impact senior organisations had on policies, he clearly noted the limitations inherent in senior

empowerment: an agenda that is too broad, and a membership which has fluctuating levels of energy, make for inconsistent success. However, when Ellen commented that 'death can happen at any time', she invited us all to engage with challenging discourses around ageing, dying and death and to give voice to the desire to grow and be nurtured in old age and death.

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Contributions to learning, clinical practice and theory

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The ideas for both papers originated some time ago, but the execution has encompassed a journey that I could not have anticipated. In this final part, three areas will be discussed in more detail: first are my personal reflections, as these had a large bearing on the project, followed by implications from both the literature review and the empirical study for clinical practice, and finally future research and theory development.

Personal reflections

Personal encounter with death

The topic area first came to my attention as a Social Gerontology student in the Netherlands when undertaking a module in thanatology. With eu/as being permitted in the Netherlands, I heard the perspectives of medical colleagues involved in eu/as requests, and was aware of friends who had considered and others who had completed eu/as. Apart from a professional interest, the topic was always going to be personally challenging. Having witnessed untimely deaths and reeled at the impact of these, confronting mortality from a research perspective, whilst keeping an eye on my inner voice, would also be a process of personal discovery. However, I had not anticipated that while working on this project, I would come

face to face with the death of my father, who passed away unexpectedly. In his final five days, I came close to the two subject areas of my thesis: advance directives and euthanasia.

With undertaking a Doctorate in Clinical Psychology, apart from developing my academic skills, I was also fulfilling a dream held by my parents (living in the Netherlands), who as war children had not been able to complete their education. I recall telling my parents, to ‘keep breathing for another 3 and a half years’, so they could hopefully witness their daughter graduating. My father was with me on this journey for almost 2 years, in the knowledge that I was on track. I told him that I had obtained ethics approval for the empirical study, while he was in a coma.

Having been present at the end of my father’s life journey, I became part of the ‘apparent’ negotiations with the medical team around my father’s end-of-life decisions. Although he had expressed frustration with the limitations of growing old, his fear of dying had stopped him from expressing any wishes in more detail in a Dutch equivalent of an Advance Decision. Despite my interest and training, I had not encouraged nor engaged in any detailed conversations with my parents about their end-of-life wishes, thus acting in a similar fashion to the way the research participants reported their children responded to their desires to discuss this topic (Sansone & Phillips, 1995; Dea Moore & Sherman, 1999).

My father had been resuscitated twice after his initial cardiac arrest. To be told by the medical team that they had decided that he was not to be resuscitated again was confrontational, but consistent with what I had learned while preparing my literature review

about the effectiveness and possible outcomes of CPR. The fact that my mother's and my view concurred with the doctors was considered '*convenient*', as otherwise they would have '*spent some more time persuading us of their decision*'. The medical staff gave us the illusion of being involved in the decision making, yet when questioned they made it clear that only they would make the decisions, as it could '*not be expected from families to do so due to their limited medical knowledge and emotional involvement*'. This statement had remarkable similarities with the Israeli doctors' attitude in Ganz et al.'s study (2006).

When, following investigations, my father's prognosis was considered extremely poor, we were faced with an 'unambiguously negative, [real life] scenario with poor health status and poor outcome' (Sudore, Schillinger, Knight, & Fried, 2010). We talked about my father's values and his desire to remain active and independent, a theme familiar from my empirical study, which seemed incompatible with what lay ahead for him were he to survive and recover. The medical team's best interest decision and our surrogate decision concurred. They commenced 'supportive' treatment, which meant an increase in sedation and pain relief. My father passed away peacefully within 45 minutes of this treatment being started. The medical team was keen to stress that this was not euthanasia, but had I witnessed involuntary (passive) euthanasia, evidence of the 'slippery slope' or routine medical practice?

These events have helped to give my own fear of death and dying a more peaceful place in my life. Having witnessed a death that was dignified, and feeling able to continue my life has been encouraging not only for me, but also trusting that those I will leave behind one

day, will survive too. However, the grief of my mother is harder to bear and to date I remain feeling empty handed in her presence.

My attitude to AD and eu/as is unaffected as I continue to be convinced that we, given the options, 'do as we know best and when we know better, we do better' (Sharon Longshaw⁸, 1999).

Revitalisation and challenges

In carrying out this project, I have felt a resurgence of my interest in social gerontology. By choosing Foucauldian discourse analysis I have been able to explore ageing and death in a wider social, cultural and historical context, while listening to the psychological impact of these discourses on older people. Applying a new research methodology, and with that the enjoyment of learning and discovering another way of looking at the world, one that seemed at some level natural while also feeling alien, has been a pleasure. However, the actual interviews proved to be the aspect of qualitative research that unexpectedly was more challenging than I had anticipated. The competencies utilised in clinical interview, like (risk) assessment and developing a formulation, did not easily translate into a research interview setting. Developing a quick rapport with the participants proved easy, but ensuring that all aspects of the interview schedule were covered and rich data were obtained, while engaging with them in such a way so they felt they could talk freely, proved to require the acquisition of a new skill. Not disclosing or revealing any personal views in a

⁸ Sharon Longshaw was an inspirational colleague who died in 1999, mother of 3 young children and my age.

‘conversation’ about such an emotive topic felt unnatural and required constant internal monitoring. When transcribing I often urged the interviewer (i.e. me), in vain, to ask the obvious question to follow a particular line of thinking. Unlike clinical interview, there was no ‘next time’. I assume it is always easier to ‘hear’ these things with the benefit of hindsight. Surprisingly, the interviews were not challenging from a mortality perspective, but the unexpected comments, related to family relationships were confrontational. Several participants talked about having no immediate family, family living abroad or having ‘married foreigners’. These comments had personal resonance, as I am an only child, who has married a foreigner and lives abroad. They commented that they had not felt able to have conversations with their children because they saw them infrequently and did not want to keep revisiting the topic of death and dying. As a clinical psychologist I am more likely to have conversations with ‘strangers’ about death and dying, than I do with my own family. This is partly understandable as the nature of professional relationships is less emotive, of much shorter duration, and provides stricter boundaries. Having realised this, it makes it even more important that in my professional capacity, I facilitate communications about death and dying, where appropriate, within family units of older people. I will discuss this in more detail under implications for clinical practice.

Implications for clinical practice

While eu/as remain illegal within the UK, clinicians will need to work within the current legal framework. Advance Directives (AD) is the legal vehicle for (older) people to express

their end-of-life wishes. However, the literature review and empirical study point to several areas where a clinical psychologist can facilitate exchanges regarding the end-of-life choices as well as be mindful and alert to the influences discourses about older people can have on service provisions.

Communication

Both papers emphasize the need to encourage and facilitate communication about end-of-life issues and to find not only the right discourses but also the courage to address these issues, which seem to be taboo in our society. As a member of a multidisciplinary physical health team (Sears & Stanton, 2001), a clinical psychologist can undertake end-of-life conversations themselves, and facilitate colleagues carrying out pre-diagnostic counselling where appropriate, sharing a diagnosis and prognosis as and when required, providing post-diagnostic counselling and making patients aware, again when appropriate, of the possibility of writing an AD (Department of Constitutional Affairs, 2007).

Multidisciplinary team members can complement each other in carrying out the above tasks (Mezey, Botrell, & Ramsey, 1996; Jezewski, Meeker, & Robillard, 2005) and clinical psychologists can train colleagues in these communication skills and provide debriefings after challenging consultations and decisions. Supervision of colleagues and facilitation of reflective practice groups can help to address some of the personal barriers that colleagues can experience when supporting a person whose end-of-life is approaching and who is making challenging decisions (British Psychological Society, 2011).

Apart from providing a therapeutic space for people to consider their end-of-life decisions, and assisting colleagues in facilitating these discussions, assessment of capacity and the mental health of the person making end-of-life decisions are competencies that clinical psychology can bring to the team (Blank, Robinson, Prigerson, & Schwartz, 2001). There are however problems when different assessments are being carried out by different specialists. Most clinicians will probably have known the person for a relatively short period, in already strenuous circumstances, with possible fluctuating levels of consciousness, and in a clinical setting outside their familiar social context. The structure of the health service provision in the UK seems to contribute to the compartmentalisation of the person, with the GP usually passing on their clinical responsibilities to a specialist or palliative care team. This is in contrast with the Netherlands where it is more likely that the GP remains involved and provides end-of-life care. Based on an established relationship with the older person, the GP is better placed to assess the capacity, mental health and any other factors that could be impacting on the older person's end-of-life wishes (Norwood, 2007). The older person tends to be known in an intimate manner and the established relationship between the GP and the older person is reciprocal and mutual. Kimsma (2010) suggest that a 'medical friendship' develops, in which the physician acts as teacher or friend. This type of relationship is more likely to facilitate open communication regarding deeply emotional and private issues, but challenges the well-established professional boundaries (Tulsky, 2010). However, when Trice and Prigerson (2009) reviewed the literature around communication in end-stage cancer, they found that where physicians and patient had known each other for longer, communication might be affected by this and appeared less open and frank.

When working with older people in mental health services, dying and death are usually discussed as part of a (suicide) risk assessment. The clinical competence is to know when and if to pursue the unspoken with clients who are not expressing suicidal thoughts, but who are due to their age and other health co-morbidities closer to death. Cognitive changes might well impact on their capacity to make informed decisions, but the emotional component and distress of end-of-life will still require time and skills to support, facilitate and comfort.

Although eu/as is illegal in the UK, this does not preclude clinicians being confronted in their clinical work with people who have chosen assisted suicide in Switzerland. Knowing professional responsibilities and boundaries, and seeking supervision are essential to ensure a respectful management. Working with the family and the wider system is essential in ensuring a satisfactory outcome for all involved, as evidenced by Detering, Hancock, Reade, and Silvester (2010), who showed that those family members involved in the decision-making had less symptoms of PTSD and depression when grieving.

Depression and suicide

One of the participants referred to suicide as a means of ending his life if 'he was no longer able to wash and clean his teeth'. Jamison (2000) described how people were concerned that if they expressed their end-of-life wishes, doctors could consider them a potential suicide risk. However, it is well documented that low mood, anxiety and depression can be co-morbidities in end-of-life health conditions (Blank et al., 2001) and therefore an

assessment of a person's mental health, and if indicated, treatment, are required to ensure that people can make an informed choice about their end-of-life decisions. Apart from pharmaceutical interventions, psychological approaches (Cognitive Behavioural Therapy, Mindfulness and Acceptance and Commitment Therapy) might assist in supporting the patient in appraising their options and coming to terms with their end-of-life.

The impact of mental health on the options people might consider at the end of their life, is one of the arguments against legalising eu/as. However, the question is whether older people do utilise the suicide option in the absence of other end-of-life options? People over the age of 65 have the highest completed suicide rates and the suicide risk is cumulatively greater when the number of physical illnesses increases. A review of coroner's reports of people who committed suicide in the UK, revealed that 10% had a chronic or terminal condition (Bazalgette, Bradley, & Ousbey, 2011). Furthermore, suicide among older people can be considered to be a potential significant societal problem in the future as the 'baby boom' generation might be more vulnerable to suicide. Sociological studies indicate that suicide rates tend to be higher in age groups constituting a large part of the population (Bonnewyn, Shah, & Demyttenaere, 2009). The role of prevalent discourses about ageing, dependency and dying on the behavior of certain groups might be considered useful when trying to understand this phenomenon. Clinically, an awareness of suicide risk factors, like depression, physical health, gender, bereavements, is required, as well as an assessment and monitoring of suicide risk. A suicide attempt in older people usually reflects a real wish and intent to be dead and needs to be taken seriously. Interestingly, Norwood, Kimsma, and Battin (2009) report that GPs in the Netherlands consider a wish to be dead as a contra-

indication for a eu/as request.

Dementia and end-of-life wishes

The end-of-life wishes of older people with cognitive difficulties and dementias have not been discussed in the two papers due to the word limit. However, with an increase in the older adult population and prevalence levels for dementia at 20% for people over the age of 85, for many ‘losing ones mind’ can be a great fear for many in old age. Societal views and discourses about dementia are also likely to affect the wishes expressed in ADs for a time when a dementia is diagnosed (Gastmans & De Lepeleire, 2010).

ADs that express wishes about end-of-life care when diagnosed with a dementia are considered problematic as the person with dementia can contradict the wishes expressed in their AD (Hertogh, de Boer, Dröes, & Eefsting, 2007). Winter, Moss, and Hoffman (2009) showed that competent people change their mind as to what they consider a tolerable and acceptable standard of living. The apparent loss of insight in an advanced dementia might make the assessment of unbearable suffering much harder as well. Euthanasia, defined as intentionally terminating a person’s life at their request, can be challenged in a person with dementia, as their capacity might well be queried. Dutch physicians do not adhere to AD requests for euthanasia for a person with dementia who has become incompetent (De Boer, Dröes, Jonker, Eefsting, & Herthogh, 2011). However, when physicians in the Netherlands were surveyed regarding the end-of-life care for people with dementia, in 53% of cases an explicit intention to hasten death was reported. In 41%, antibiotics or other treatment were withheld with an acknowledged increased chance or certainty of a hastened death (Van der Steen, Van der Wal, Mehr, Ooms, & Ribbe, 2005).

Dementia is generally not considered a terminal condition and as a consequence older people with dementia tend not to have access to specialist palliative care. To obtain access to the service, accuracy of prognosis is required as well as a reconsideration of what constitutes futile medical treatment, which can be even be more of a value-based judgement when a co-morbid diagnosis of dementia is present. As most people with dementia die in a health care institution, these settings will benefit from clear policies regarding their responsibilities and duties at the end of a resident's life (Gastmans & De Lepeleire, 2010).

Improving care provision

Most participants had witnessed others receiving care and treatment, which they had regarded as undignified, disrespectful and sometimes unwanted. Although some aspects of the care and treatment might be unavoidable and inherently challenging for people, and quality of care did not automatically reduce a wish for eu/as (Seale & Addington-Hall, 1995), there are calls to improve the quality of care provided to older people in hospitals. The Older People's Commissioner for Wales published a report called 'Dignified Care?' (2011), addressing the need to increase the dignity of older people when they are receiving care in acute hospitals. A similar report by the Parliamentary and Health Service Ombudsman: 'Care and Compassion?' (2011), regarding the care for older people in the NHS in England, was the basis for Tilby (2011, Appendix 3.1) in her reflections for Thought for the Day: *Do not cast me away in the time of old age; forsake me not when my strength fails. It could be a plea to a family, to a nurse, to the staff of a care home. There is something in us, which is frightened by the sickness and weakness of the elderly and would*

rather look away. The deterioration of the body and the distress of the mind hurt us. We revolt against it'.

The sentiment is one that refers to deep-seated personal and societal discourse about aging and dying, and she suggests we all need to engage in '*praeparatio mortis*', so as to overcome our fear and revulsion, from which we can then care for older and dying people. Ideally, professionals themselves would undertake this work, before they assist other colleagues and patients. Personal therapy and supervision might assist with this preparation and can raise awareness of how the discourse employed when referring to older people and dying, can affect the way we interact and care for them. This, combined with improvements in communication and monitoring of older people's mental health, will contribute to an improved person-centred service, where dignity can be maintained (Kitwood, 1997).

The care for people with dementia also requires improving and the Welsh Government 1000livesplus (2010) serves as guidance to improve care in NHS settings, in which improved working relationships with other statutory and voluntary services are being encouraged. The care standards in private care homes remain a challenge.

Policy vigilance

Whether training initiatives and procedural changes will have the desired impact on care for older people is not certain. The comments of Tilby refer to a fear of facing our own decline and mortality, which leads us to dehumanize and alienate those around us who are deteriorating and dying. To overcome this death denial, a more radical approach might be

needed. The two studies revealed that the (conscious and unconscious) discourses about older people and the medicalisation of dying are powerful and have permeated society. Alertness is required to language and discourses used by policy makers and government. Although the National Service Framework (NSF) for older people for England (Department of Health, 2001) and Wales (Welsh Assembly Government, 2006) both have as one of their objectives to eradicate age discrimination in health care, in other policies the government refers to 'burden of ageing' (Department of Health, 2011) and the un-affordability of pensions due to increased life expectancies (HM Treasury, 2011). The English NSF's first sentence in the foreword is: *Just like the rest of us, older people want to enjoy good health and remain independent for as long as possible*. Not only does the author naively seem to ignore the reality of natural changes in health that occur when growing older, the first sentence separates older people from 'us', presumably younger people. This in itself reflects implicit age discrimination. In the Welsh NSF, one standard is to 'challenge dependency'. Becoming dependent on others will be a realistic prospect for a lot of older people at some point in their life (O'Connor, 2009). There seems to be an implicit assumption that dependency is an undesirable state of being, ignoring the interdependency and interconnectedness between members of a community, that emerged as a strong theme in the first paper (Seymour, Gott, Bellamy, Ahmedzai, Clark, 2004).

When contributing to the development of policy and commenting on consultation documents, clinical psychologists should be exposing the implicit assumptions and discourses about older people and end-of-life, which are maintaining unequal power relationships and therefore the status quo of poor quality care.

Implications for future research and theory development

Methodological pluralism

Being a novice in qualitative research presented a range of challenges, from selecting the methodology to suit the research question, the design of the interview schedule and the analysis (Burck, 2005). If the research question had been to find out the attitudes of older people towards eu/as, a quantitative research design would have been more suitable. The more fashionable Interpretative Phenomenological Analysis was not appropriate as interviewing people who have 'lived the experience' would have posed an ethical and recruitment challenge. From a gerontological perspective, the discourses from older people around eu/as helped to gain an insight into the position that older people possibly hold in society, the power dynamics at play that maintain the status quo, and the impact of these discourses on their experiences.

The qualitative approach in the empirical paper guided the research question in the literature review. Having initially considered reviewing the often researched, facilitating factors in completing ADs, the underlying assumption about the benefits of having an AD became questionable. It is important to ascertain and acknowledge the, usually implicit, assumptions that underpin quantitative research, and to critically evaluate them, alongside any possible flaws in research design, analysis and results interpretation. When evaluating the outcome studies related to ADs, it became apparent that underlying the assumed benefits of self-determination, expressing ones end-of-life's wishes and having them

considered, and their assistance to surrogates decision making, an implicit assumption was that the medical profession makes the ultimate end-of-life decisions (Ost, 2010).

Carrying out qualitative research, and choosing a particular research stance, also creates a bias in the reporting. It is acknowledged that qualitative research does not aim or pretend to establish the truth, but merely shed another light on the individual's experiences as constructed at that moment in time, with the interviewer. To adopt a discourse approach locates the experiences in established and maintained power relationships as they exist in communities and wider society. Those conducting psychological research must seek to have an awareness of the power structures that might be at play in the phenomenon under study and as such research cannot be a-political or outside a discourse, whether that is diagnostic criteria or intervention outcomes. The involvement of lay people and service user representatives in identifying research topics can assist in ensuring that researchers become aware of discourses that might be influencing those not holding, exerting or maintaining power.

Critique of Discourse analysis using Foucauldian concepts.

From an epistemological perspective the research question was well suited to discourse analysis. As the expression of power plays a major role in euthanasia and assisted suicide and the related debate, the choice to apply a Foucauldian perspective to any emerging discourses was also a logical step. However, this choice of methodology brought challenges to the research. Two critiques will be presented in turn: Foucault's assumptions about the

role of power and discourses in society, and the impact of the power of the researcher in discourse analysis in terms of data creation, analysis and interpretation.

Foucault's perspective on power

Foucault's philosophical stance might benefit from being considered in the light of his personal life experiences. It is noted in his biography (Gutting, 2005) that his father was an authoritarian physician and his mother's wish to become a physician had not been permissible for women at that time. Foucault is described as an emotionally troubled young man and tormented by his homosexuality. It is speculated that a suicide attempt in late adolescence, young adulthood might have been the reason for Foucault receiving psychiatric care. His preoccupation with medicine, mental health, deviance and power perhaps should be understood against these experiences. The emphasis on power could be related to his early parental attachment, especially with his father. The experience of being a psychiatric in-patient during the first half of last century is likely to have further shaped his ideas about the power of the medical profession, the creation of mental illness, the control over the physical body, and the experience of being under constant surveillance. After Foucault's initial attention on the development (genealogy) of discourses, he began to attend to how, with increases and changes in knowledge, new power relationships were being embodied in actions. Discourses created new realities and with this, institutions in which power relationships were being executed, emerged, i.e. education, prisons and hospitals. His conceptualisation of power relationships created positions of 'objects' and 'subjects' and the idea of the surveillance made the discourse appear negative and paranoid,

with the person at the mercy of disciplinary and dominating powers, over which no control could be obtained. Foucault appeared to ignore any possible positive influences of knowledge or power in society and institutions, for example the impact advances in medical knowledge have had over recent decades in extending people's life span (although not always quality of life), reducing suffering and enhancing choice. The surveillance that occurs in the medical care, can be seen as benevolent and beneficial to the recipients, not only for their physical health, but also for a psychological sense of being cared for, feeling safe and worthwhile. The participants clearly articulated these positive aspects to the physicians' views regarding end-of-life decisions.

Assuming he was aware that his mother's choices were limited due to gender discrimination, it is interesting that he makes no specific reference to the position of women in society. Although the feminists have embraced his thinking that power is exercised rather than possessed and expressed at the level of the body, they have criticized him for his refusal to set norms for which type of power is acceptable and for not leaving any room for resistance for the subject (<http://www.iep.utm.edu/foucferm/>). Foucault tended to focus on the individual under the influence of the power discourses and societal institutions. He paid no, to limited, attention to the possibility of individuals or (newly created) groups of individuals, who could be capable of collective group action, possibly beginning to exercise power and influence discourse. However, there are examples where individuals are challenging the prevalent discourses and power structures, e.g. Debbie Purdy, who legally challenged and got the law clarified regarding the consequences for assisting somebody in suicide. The discourse around assisted suicide might alter as a consequence of this

clarification in the law. Foucault's attempts to understand how historical developments changed power relationships and discourses, might assist when considering how discourses could be influenced and affected in the future.

Despite these limitations and cautions that need to be exercised when working with Foucauldian concepts of power, his angle on understanding language as a reflection of societal (power) discourses and their impact on the internal world of individuals, add an alternative way of studying psychological concepts in a historical, societal context.

The trouble with discourse analysis

Normally discourse analysis is utilized to analyse existing texts, i.e. policy documents, media reports or other conversations that occur spontaneously. These texts are seen to be representations of naturally occurring discourses within certain discourse planes (Jäger & Maier, 2009), reflecting 'permitted discourses'.

Focus groups can be a good method to obtain data, where the interviewer's power is diluted by the power of the group members, and more spontaneous conversations can emerge. Due to the nature of the topic, which tends to create strong emotions in society, it was considered a possibility that people might not come forward to express their views, if they were not sure of the positioning of the other group participants. It was therefore decided to conduct semi-structured interviews to create the data source, but with this a major challenge was introduced. An interview schedule creates an artificial structure to the language, which can interfere with naturally occurring discourses. This impact is likely to be caused by the

‘power’ exercised by and the power relationships established with the interviewer. The interviewer/ researcher him/herself takes part in and is part of one or more discourses, and steers the interview via the created interview schedule and by pursuing certain aspects in the interview.

In order to reduce and acknowledge this power impact, the interviewer/ researcher routinely declares their interest in the topic and attempts to ascertain how this could potentially influence the nature of the interaction as well as the subsequent interpretations. As discourse analysis does not assume to ascertain the truth, but merely offer an alternative interpretation of a ‘reality’ as constructed by different discourses, the task for the researcher is to make the interpretation as transparent as possible to the reader. For this the power of the interviewer/ researcher and the power relationship with the people interviewed needs to be explicated as much as possible, although this is not always an easy, or indeed a conscious process.

Several considerations were given to the potential influence of power in the research project. The invitation to take part in the research was phrased as neutral as possible, without hinting at the possible positioning of the researcher in the debate. However, as the first participant knew the interviewer was Dutch, a country where eu/as is legalised, it was decided to declare this to all interviewees at the time of the interview. Although it is highly unlikely that the decision to take part in the study was influenced by this knowledge, the declaration at the start of the interview and a possible assumption on the part of the participant about the interviewer’s position, might well have encouraged the participants,

who all appeared to be more or less in favour of eu/as, to utilise a discourse that would reflect their perspective more strongly. It is not clear how this declaration would have impacted on people who positioned themselves not in favour of eu/as. Consideration would need to be given as to how to recruit those opposing or ambivalent to eu/as in an explorative study, and how they would position the researcher in the debate.

At a practical level, the older people had a choice of venue for the interview. Five people opted to be interviewed at home. The interviewer hereby enters the participant's private space and a shift in control and power takes place at this stage. Similarities arise with the impact of venues on clinical interviews, where during appointments at the client's (care or nursing) home or on hospital wards, the clinician faces different boundary and power issues.

The interviewer followed the interview schedule, which was based on existing literature regarding eu/as. For the Foucauldian concepts to be considered in the discourse analysis, certain questions were included: the participants' knowledge base of eu/as, the historical development of their views, and their positioning in the debate. Hence it can be said that the interviewer/ researcher could have encouraged certain discourses in an artificially created exchange. Although this confound also occurs in quantitative research, where the researcher predetermines which concepts are being studied, it is important to be explicit and aware of the power issues in a methodology that is interested in power itself.

It might be that the more unconscious phenomenon of transference and counter transference, known to occur in clinical settings, influenced the interviews, especially with a research topic potentially emotive for both interviewer and interviewee. While the interview schedule was adhered to with appropriate flexibility, some interviews proved more difficult to end than others. Comparing notes with fellow qualitative researchers revealed that they had not experienced similar issues with ending their interviews. An interpretation became available after the sixth interview, where the participant appeared to be more at ease with the prospect of their end-of-life, which made ending the interview easier. It appeared when the participants had been hesitant and ambivalent about how they wished to end their life, the interviewer had become unsure about the 'ending' of the interview. The impact (and power) of transference and counter transference impacting on interviews with a range of topics might require further exploration and study.

Other qualitative methods consult the participants for feedback regarding the findings, in order to ascertain the objectivity of the analysis. This could have been an option, but the participants' perspectives are no more or less 'correct' than the interpretations of the researcher. One needs to keep in mind that the nature of the enquiry is not to establish the truth, but an alternative interpretation to a phenomenon, which might guide further research.

As Foucault himself was averse to any exertion of power, he never set out any guidance regarding the method of analysis to be adopted. Others have since then developed guidance,

but there is no universally ‘agreed’ and well-developed method, unlike for Interpretive Phenomenological Analysis (Smith, Flowers & Larkin, 2009).

Fairclough suggested analysis at three levels: socio-cultural, discourse practice and the textual level (McIntyre, Francis & Chapman, 2012). The socio-cultural level tries to establish the social context in which the text is produced and uncover the implicit unspoken and unstated assumptions. The discourse practice level is concerned with the production, distribution and consumption of the text. The minutiae of a text is of concern at the textual level, how it is formed and what particular vocabulary and style are used to produce meaning. Georgaca and Avdi (2011) suggested a five level analysis. Firstly, language is seen as constructive, hence objects are constructed by the text and thus create specific versions of the phenomena and processes. Secondly, the underlying intentions of the discourse are revealed in action orientation. Thirdly, positioning occurs through the identities made relevant through specific ways of talking, either in the specific interaction or in the wider discourse. At level four, discourses are explored to see how through dominant discourses, institutional practices are supported, enabled and maintained. At the final level, the discourses are examined for their impact on subjectivity: how the adoption of certain subject positions has effect on the individual’s thinking, feeling and experiences. Jäger and Maier (2009) emphasize the structural characteristics of discourses. Discourse fragments make up discourse strands, which are the concrete utterances of the more abstract discourses. Different discourses can operate at different discourse planes such as media, politics etc. Discursive events can influence the discourses, e.g. Terry Pratchett’s public lecture in favour of eu/as, the film ‘ A short stay in Switzerland’. The discourse position that subjects, including individuals, groups and institutions take when participating in and

evaluating discourses, can reflect the enmeshment of the subjects in the discourses. The variety of possible ways of conducting discourse analysis, makes the choice of applying a Foucauldian discourse analysis more open to challenges.

The analysis of the data will also be influenced by the discourses the researcher is enmeshed in. Separating the role of the interviewer from the person analysing the data, would introduce further discourses and power relationships but a more 'objective' stance might be obtained. The researcher attempts to be transparent by illustrating the discourses with extracts from different text sources. But, as discourse analysis is interested in the multivoicedness of the discourses as well as discourse that are omitted or 'not permitted', the knowledge, positioning in the discourses and related power of the researcher will have an impact on the interpretations. Apart from awareness, transparency and critical outlook on the side of the researcher, these influences can only be reduced, rather than eliminated.

Autonomy and the medical profession

Autonomy and self-determination were important values for older people when considering their wishes in ADs and eu/as. One of the encountered challenges in seeing their wishes implemented, seemed to be the perspectives of the physicians. The ambivalence of some physicians regarding ADs is beginning to emerge in some studies. The fact that few physicians had been involved in drawing up the ADs, but were asked to implement the AD (Schiff, Sacares, Snook, Rajkumar, & Bulpitt, 2006) might well be challenging the authority physicians have acquired according to Foucault (Dreyfus & Rabinow, 1983). Obtaining a better understanding of the responses of physicians, considering the apparent

reversal of power and possibly related defensive action, could contribute to enhancing the communication between physician and their patients.

The emotional impact of assisting in suicide or euthanasia on physicians in the countries where eu/as is permitted is beginning to emerge (Kimsma, 2010; Norwood, 2007). Less is known about the emotional impact on physicians in other countries where ‘passive’ euthanasia is permitted and carried out and the possible impact these experiences might have on a physician’s well-being and further practice.

Older people’s wor(l)ds

There are only limited numbers of qualitative research papers available where the views of older people regarding eu/as are reported. They are normally reflected in samples where participants are physically unwell and are studied as part of a larger patient population. Leichtentritt & Rettig (2000) interviewed older Israelis regarding their views on euthanasia, but acknowledged that their accounts need to be understood in the light of a Jewish community who have survived the Holocaust, and for whom euthanasia is associated with genocide (Leichtentritt & Rettig, 1999). Further qualitative research with samples from more diverse backgrounds (faith, age, physical health) in countries where eu/as is and is not legalised, will contribute to the narrative of older people’s views regarding ageing and choice in one’s death. Possible different discourses regarding death and ageing might emerge in other cultural, religious and economic communities. Sociological and anthropological research can assist in studying the changing place of death in societies and how this reflects the position of older people.

Being able to conduct in depth interviews with older people who have chosen to travel abroad to obtain assistance in ending their life, can help to enter the world of lived experience and shed more light on what is required for individuals and their social networks to ignore and overcome legal barriers and societal taboos.

Most of the current research focuses on the experiences and characteristics of one of the participants in end-of-life decisions: either the patient, their family, wider support networks, health professionals or the legal system. Further understanding needs to be developed about the complex interplay between the characteristics and experiences of each of the participants and the role that possible discourses might play in maintaining the current situation.

Theoretical developments

The impact of (unconscious) societal discourses about ageing and dying on the individual's psychology is emerging in the empirical paper and the literature review. Some discourses seem to have become internalised by participants and reinforced by behaviours from powerful others. Evidence from other sources, like media (Hausman, 2004) and government policies (O'Connor, 2009), seem to support that powerful discourses exist about ageing and dying.

The process of exploring if and how discourses are reflected in the gerontological theories could be considered. For example, while the activity theory (Havighurst, 1961) postulates

that maintaining involvement with the world facilitates successful ageing, the disengagement theory (Cumming & Henry, 1961) suggests that a gradual withdrawal is required in order to prepare for death. This theoretical dichotomy was also reflected in Kelner's study (1995), where there appeared to be two types of older people, the ones that wanted to stay active and in control, while others disengage and delegate.

Currently, society does seem to value activity, control and autonomy, which appear to be more in keeping with the discourses of a younger generation. Older people seem to be either measured against this standard or otherwise, due to a lack of a reference group as described in the Social Breakdown theory (Kuypers & Bengtson, 1973), are vulnerable to external labelling. As seen, the discourses about older people in society are less than positive and give older people little if no power to alter their position.

It will be important to undertake cohort as well as longitudinal studies to see if and how the discourses change from a historical as well as developmental perspective. As some participants commented, previous generations seemed to tolerate their dying experience, while their cohort asked questions and referred to having got used to exerting control over their lives.

Few theories comment on preparation for end of life and death. Freud (1985) was concerned with our denial of death (Zimmerman, 2004), while Kübler-Ross (1973) described the stages of grief, but neither were specifically addressing end of life in old age. Erikson's psychosocial developmental theory (Erikson, Erikson, & Kivnick, 1986) is one of the few psychological theories which addresses death, and the challenge to achieve ego

integrity and wisdom in old age. His theory is placed in a historical and societal context and allows for the impact of external forces on intra-psychological processes. Erikson's reviewed his theory in his old age and suggested that all eight stages of life are being reactivated in old age. An early review of the interviews does reveal reference to the 'crises' in the different life stages, e.g. trusting others, desire for autonomy, sense of shame, challenges to one's identity, concern for the next generation and a making up an end-of-life balance. Evaluating whether discourses have an impact on the emphasis participants put on certain ego-strengths, might be of interest to develop our understanding of ageing and dying.

Most psychological theories around ageing and dying were developed in the last century; perhaps it is time that psychology re-engages with this area again (Kastenbaum, 1982; Feifel, 1990).

Conclusions

Two themes have emerged across both studies:

At an individual level, the importance of listening and talking, for all people involved in end-of-life matters is paramount in both studies. Dying is a process of letting go and for this, relationships and connectedness are vital. Although autonomy and control seem desirable at the end phase of our life, we cannot alter its ultimate outcome.

At a collective level, society's practice not to discuss and face mortality will need to be countered. The effects of not doing so, maintains a powerful discourse about ageing and dying which leaves an ever-growing part of our community voiceless and neglected. As we all hope to grow old, this *is* all our business.

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School of Psychology Ethics Application

School of Psychology ethical approval form

Ethics Checklist

Before submitting this form, please check that you have:

- Read and followed the advice provided in the *Ethics Guidance & Procedures* (provided in the ethics folder online)
- Provided names and email addresses for **all** investigators (as this is the means we will use to contact you regarding the outcome of your ethics review)
- In Part One of these forms, ticked **either** Box A **or** Box B and provided the further information required
- In Part Two of these forms, provided on a separate sheet further information on any risks likely to be incurred in conducting the study
- Attached consent forms and information sheets
- Attached any questionnaires to be used in the study

And, additionally:

- If working with children or other vulnerable populations, ensured that all investigators working directly with participants have arranged for a CRB check to be conducted.
- If your proposal is to be submitted to an NHS LREC, attached the NRES and R&D forms (and followed the information provided in the *Ethics Guidance & Procedures* on completing certain questions)

SCHOOL OF PSYCHOLOGY ETHICAL APPROVAL FORM

Please complete all parts to this form.

Please attach consent and information/debriefing sheets to all applications.

Date: 27th August 2010

Tick one box: STAFF PROJECT MASTERS PROJECT PHD PROJECT

CLINICAL PSYCHOLOGY PROJECT UNDERGRADUATE PROJECT

CLASS DEMONSTRATION

What is the broad research area? Vision and the Brain Clinical & Health

Language and Development Other

Who is the funder of the research? NWCPP

Title of project: How and where do older lay people position themselves in the euthanasia and assisted suicide debate? A qualitative exploration.

Name and email address(es) of all researcher(s):

Drs. Carolien Lamers c.lamers@bangor.ac.uk

Name and email address of supervisor (for student research):

Dr Rebecca Williams Rebecca.williams5@wales.nhs.uk

Study Start Date: September 2010

Study End Date: 31 December 2011

	YES	NO
Is your project in the area of Health and Social Care requiring sponsorship by the University of Wales, Bangor? If yes, please complete your ethics application in NRES format and submit an NHS R&D form alongside it. You should still complete all sections to this form, but do not need to supply the additional information requested in boxes A or B of Part 1.		X
Does your project require scrutiny from an outside body that has its own forms? If yes, please complete your ethics application using the forms required by that outside body. You should still complete all sections to this form, but do not need to supply the additional information requested in boxes A or B of Part 1.		X
If a student project, is this part of the supervisor's ongoing research that has been previously reviewed and approved? If yes, please give the proposal number of the approved research project, and complete all sections of this form.	Proposal no.	X

PART ONE: ETHICAL CONSIDERATIONS

		YES	NO	N/A
1	Will you describe the main experimental procedures to participants ⁹ in advance, so that they are informed about what to expect?			X
2	Will you tell participants that their participation is voluntary?	X		
3	Will you obtain written consent for participation?	X		
4	If the research is observational, will you ask participants for their consent to			X

⁹ In questions 1-9, if participants are children, please consider the information that you will supply to the legal guardian in each case.

Ethics Application

	being observed?			
5	Will you tell participants that they may withdraw from the research at any time and for any reason?	X		
6	With questionnaires, will you give participants the option of omitting questions they do not want to answer?			X
7	Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?	X		
8	Will you debrief participants at the end of their participation (i.e. give them a brief explanation of the study)?			X

If you have ticked **No** to any of Q1-8, but have **ticked box A** overleaf, please give an explanation on a separate sheet.

[Note: N/A = not applicable]

		YES	NO	N/A
9	Will your project involve deliberately misleading participants in any way?		X	
10a	Is there any realistic risk of any participants experiencing either physical or psychological distress or discomfort? If Yes , give details on a separate sheet and state what you will tell them to do if they should experience any problems (e.g., who they can contact for help)	X		
10b	Is there any realistic risk of any participants experiencing discomfort or risk to health, subsequent illness or injury that might require medical or psychological treatment as a result of the procedures?			X

Re question 10a

Assisted suicide and euthanasia are criminal offences in the UK and as such the topic is an emotive one, not least because of the existential nature of the debate. Although the participants are not facing an imminent death, due to their age they will all experience closer proximity to death and will have experienced bereavements. Thus the interview could trigger anticipatory anxiety and traumatic experiences and memories. However, participants are healthy older people without mental health problems and thus the probability of any adverse effects of taking part in the study is very low.

The PI is a qualified clinical psychologist, who as part of her NHS post routinely works with clients who are emotionally distressed. If the participant indicated that he/ she

would like further support and advice, information about service options like the GP, primary care counseling services or Cruse can be discussed and made available to them.

If you have ticked **Yes** to 9 or 10 you should normally **tick box B** overleaf; if not, please give a full explanation on a separate sheet.

11	Does your project involve work with animals? If yes, please tick box B overleaf.		X	
12	Does your project involve payment of participants that differs from the standard rates? Is there a significant concern that the levels of payment you offer for this study will unduly influence participants to agree to procedures that they may otherwise find unacceptable? If yes to either, please tick box B and explain in point 5 of the full protocol.		X	
13	Do participants fall into any of the following special groups? If they do, please refer to BPS guidelines, and tick box B overleaf. Note that you may also need to obtain satisfactory CRB clearance.	Children (under 18 years of age) N.B. You must ensure that you have made adequate provision for child protection issues in your protocol	X	
		People with learning or communication difficulties N.B. You must ensure that you have provided adequate provision to manage distress	X	
		Participants covered by the Mental Capacity Act: i.e. Adults over 16 years of age who lack the mental capacity to make specific decisions for themselves. You must ensure that you have appropriate consent procedures in place (See guidance notes below) Some research involving participants who lack capacity will require review by an NHS REC. If you are unsure about whether this applies to your study, please contact the Ethics Administrator <u>in the first instance</u>	X	
		Patients N.B. You must ensure that you have provided adequate provision to manage distress.		
		People in custody	X	
	People engaged in illegal activities (e.g. drug-taking)		X	
	Participants recruited from one of the Neurology Patient Panels or the Psychiatry Patient Panel and, if so, has the protocol been reviewed by the appropriate expert/safety panel?		X	
	Physically vulnerable adults N.B. You must ensure that there is a person trained in CPR and seizure management on hand at all times during testing.		X	
14 Does your project require	MRI		X	
	TMS		X	

use of any of the following facilities and, if so, has the protocol been reviewed by the appropriate expert/safety panel? If yes, tick Box B overleaf and supply evidence that the appropriate panel have endorsed your study.				
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Mental Capacity Act 2005

The act provides a comprehensive legal framework for decision making adults, aged 16 or over, when, because of specific mental disability (defined as an impairment of or disturbance in the functioning of a person’s mind or brain), they lack the mental capacity to make specific decisions for themselves.

The Act enshrines several key principles:

- A person must be assumed to have capacity unless it is established that he/she lacks capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him/her do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he/she makes an unwise decision.
- Any decision made under this Act on behalf of a person who lacks capacity must be made in her/his best interests.

Intrusive research on people lacking capacity to consent is unlawful unless:

- The research is approved by specified body (LREC/MREC etc)
- It relates to the person’s condition or treatment, and has negligible risks
- It cannot be done as effectively on people who have capacity to consent
- Stringent safeguards are put in place, including consultation with carers.

Researchers conducting studies involving individuals lacking capacity must familiarise themselves with their responsibilities under the law and ensure proper approval mechanisms and appropriate consent procedures are in place.

There is an obligation on the lead researcher to bring to the attention of the School Ethics and Research Governance Committee any ethical implications not clearly covered by the above checklist.

PLEASE TICK **EITHER BOX A OR BOX B OVERLEAF AND PROVIDE THE DETAILS REQUIRED IN SUPPORT OF YOUR APPLICATION.**

Please tick

A. I consider that this project has no significant ethical implications to be brought before the Departmental Ethics Committee.	
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Give a brief description of participants and procedure, including information
(1) hypotheses,
(2) participants & recruitment
(3) research methodology, and
(4) Estimated start date and duration of the study.
Start date of the study: Completion: Please attach consent and debrief forms.
(5) For studies recruiting via SONA please provide the summary of the study that will appear in SONA to inform participants about the study. N.B. This should be a brief factual description of the study and what participants will be required to do.

Please tick

<p>B. I consider that this project may have ethical implications that should be brought before the Departmental Ethics Committee, and/or it will be carried out with children or other vulnerable populations.</p>	<p>X</p>
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Please provide all the further information listed below in a separate attachment, in this order.

1. Title of project
2. The potential value of addressing this issue
3. Brief background to the study
4. The hypotheses
5. Participants: recruitment methods, age, gender, exclusion/inclusion criteria
6. Research design
7. Procedures employed
8. Measures employed
9. Qualifications of the investigators to use the measures (Where working with children or vulnerable adults, please include information on investigators' CRB disclosures here.)
10. Venue for investigation
11. Estimated start date and duration of the study (N.B. If you know that the research is likely to continue for more than three years, please indicate this here).
12. Data analysis
13. Potential offence/distress to participants
14. Procedures to ensure confidentiality and data protection
15. *How consent is to be obtained (see BPS Guidelines and ensure consent forms are expressed bilingually where appropriate. The University has its own Welsh translations facilities on extension 2036)
16. Information for participants (provide actual consent forms and information sheets) including if appropriate, the summary of the study that will appear on SONA to inform participants about the study. N.B. This should be a brief factual description of the study and what participants will be required to do.
17. Approval of relevant professionals (e.g., GPs, Consultants, Teachers, parents etc.)
18. Payment to: participants, investigators, departments/institutions
19. Equipment required and its availability
20. If students will be engaged a project involving children, vulnerable adults, one of the neurology patient panels or the psychiatric patient panel, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)
21. If students will be engaged in a project involving use of MRI or TMS, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)
22. What arrangements are you making to give feedback to participants? The responsibility is yours to provide it, not participants' to request it.

1. Finally, check your proposal conforms to BPS Guidelines on Ethical Standards in research and sign the declaration. If you have any doubts about this, please outline them.

PLEASE COMPLETE PART TWO OVERLEAF.

PART TWO: RISK ASSESSMENT

If you tick “yes” to any of the questions in the table below, please outline on a separate sheet the probability and significance of the risks involved and the means proposed for the management of those risks. Where relevant, please also describe the procedures to be followed in the event of an adverse event or emergency.

		YES	NO	N/A
1	Is there significant potential risk to participants in any of the following ways?	Potential adverse effects		X
		Potential distress		X
		Potential for persisting or subsequent illness or injury that might require medical or psychological treatment		
2	Is there significant potential risk to investigator(s) in any of the following ways?	Potential risk of violence or other harm to the investigator(s) (e.g., through work with particular populations or through context of research).		X
		Potential risk of allegations being made against the investigator(s). (e.g., through work with vulnerable populations or context of research).		X
3	Is there significant potential risk to the institution in any way? (e.g., controversiality or potential for misuse of research findings.)		X	
4	Is there significant potential risk to other members of staff or students at the institution? (e.g., reception or other staff required to deal with violent or vulnerable populations.)		X	

The following questions address specific situations that can carry risks to the investigators and/or participants. If you tick “yes” to any of the questions below, please refer to the guidance given (see *Ethics Guidance and Procedures*) on procedures for dealing with these risks and, **on a separate sheet, outline how these risks will be dealt with in your project.**

5	Does the research involve the investigator(s) working under any of the following conditions: alone; away from the School; after-hours; or on weekends?	X		
6	Does the experimental procedure involve touching participants?		X	
7	Does the research involve disabled participants or children visiting the School?		X	

There is an obligation on the lead researcher to bring to the attention of the School Ethics and research Governance Committee any risk implications of the research not clearly covered by the above checklist.

PLEASE COMPLETE PART THREE OVERLEAF.

Q 5. Lone worker policy

As the interviews can take place in venue not familiar to the PI, lone worker policy procedures will be followed. The PI will inform a senior colleague at NWCPP of the planned appointment and provide a sealed envelop with the relevant contact details for the participant and the address where the appointment is held. The PI will contact the colleague upon leaving the appointment before an arranged timeslot. In case the PI has not contacted the colleague, contact will be made via the mobile phone. When no reply is obtained, the envelope can be opened and the participant can be contacted directly. When no contact can be made, appropriate action will be undertaken.

If interviews are scheduled to take place out of office hours at the University, similar arrangements as working in the community will be made with a colleague. The University security service will be informed of presence in the building as well.

As participants are recruited from a non-patient population, no known or anticipated risks can be identified. The PI has attended de-escalation and break away training as part of her NHS employment.

PART THREE: RESEARCH INSURANCE

The purpose of this section is to decide whether the University requires additional insurance cover for a research project. In the case of student research, this section should be completed by the supervisor.

		YES	NO	N/A
1	Is the research to be conducted in the UK?	x		
2	Is the research based solely upon the following methodologies? <ul style="list-style-type: none"> ▪ Psychological activity ▪ Questionnaires ▪ Measurements of physiological processes ▪ Venepuncture ▪ Collections of body secretions by non-invasive methods ▪ The administration by mouth of foods or nutrients or variation of diet other than the administration of drugs or other food supplements 	x		

If you have ticked “Yes” to the questions above, then insurance cover is automatic for your research, once your study has been approved by the school Ethics and Research governance Committee and there is no need to do anything further.

If the answer to either of the above questions is “No,” we will supply you with a further questionnaire to complete and return to the Insurance Officer; in these cases **the research should not commence until it has been established that appropriate insurance cover is in place. Please request this questionnaire from the Ethics Administrator.**

PLEASE SIGN AND DATE THE DECLARATIONS ON THE FINAL PAGE OF THIS FORM OVERLEAF.

Declaration of ethical compliance

This research project will be carried out in accordance with the guidelines laid down by the British Psychological Society and the procedures determined by the School of Psychology at Bangor. I understand that I am responsible for the ethical conduct of the research. I confirm that I am aware of the requirements of the Data Protection Act and the University's Data Protection Handbook, and that this research will comply with them.

Declaration of risk assessment

The potential risks to the investigator(s) for this research project have been fully reviewed and discussed. As an investigator, I understand that I am responsible for managing my safety and that of participants throughout this research. I will immediately report any adverse events that occur as a consequence of this research.

Declaration of conflicts of interest

To my knowledge, there is no conflict of interest on my part in carrying out this research.

Declaration of data ownership and IPR (for students)

I understand that any data produced through this project are owned by the University and must be made available to my supervisor on request or at the end of the project. I confirm that I am aware of the University's Intellectual Property Policy and that this research will comply with it.

For Undergraduate and Masters projects, I understand that in signing this form I am certifying that the study described meets appropriate scientific standards AND that I have reviewed the procedures described to ensure that they comply with ethical guidelines as published by the BPS and described in the School of Psychology's Ethical Guidance Procedures.

(Chief investigator/supervisor)

Signed:

Date:

(Associate investigator(s)/student(s))

Signed:

Date:

For School Use Only

Reviewer 1 Name..... Approved Signature.....Date

Reviewer 2 Name..... Approved Signature.....Date

Proposal No.

1. Title of project

How and where do older people position themselves in the euthanasia and assisted suicide debate? A qualitative exploration.

2. The potential value of addressing this issue

Many debates are being held about euthanasia and assisted suicide. The views of older people, who are chronologically closer to death, are rarely recorded. The samples of terminally ill people usually involve an older patient group, but their views can be confounded by their physical and mental health. The absence of older people's views seems a substantial oversight in the current debate around active end of life decisions and might reflect the position of older people in society (Kastenbaum, 2000).

The cultural and historical context in which older people live, expresses itself in societal views of vulnerable, older, ill people in terms of usefulness, costs of care etc. Kuypers and Bengtson (1973) described the process of how this status affects older people in their Social Breakdown Syndrome. This position feeds into the concerns voiced about a 'slippery slope' (Batavia, 2000; Gordijn & Janssens, 2000; Hermsen & Ten Have, 2002), where particularly the vulnerable minorities (this includes older people) are at risk of being coerced to end their lives, as they might experience themselves as a burden.

This stereotyping is being challenged by the 'baby boomers' generation reaching middle and old age, and older people increasingly wanting to remain in control of their lives and identity (Draper, Peisah, Snowden & Brodaty, 2010). The potential challenges to

one's autonomy in later life are addressed in Erikson's Theory of Psychosocial Development (1986).

These two theoretical frameworks might well have permeated into the discourse about end of life decisions of older people. An underlying concept in both theories appears to be power. The nature of ending life through assisted suicide or euthanasia is an act that depends on assistance from others, and in most countries risks prosecution. Even in the Netherlands where euthanasia is legalized, The (2009) describes the power relationship that exists between patient and doctor, who eventually grants the request.

The views of older people can shed further light on the construction and meaning of euthanasia and assisted suicide across the lifespan. The discourse could provide insight into a possible power relationship that might exist in society in relation to older people and euthanasia and assisted suicide.

The study will contribute to the understanding around end of life decisions that older people might consider and possible (societal) values impacting on these. The outcomes will be reviewed in terms of impact on the debate and clinical practice in palliative care, geriatric and old age psychiatric services.

3. Brief background to the study

Death and dying have changed over the ages, from something that was a common occurrence, happened fast and at a young age, to a much slower transition from life to dying and death (Kastenbaum, 2000). The advances in medical technology and knowledge have made 'life' and extended living possible for people across the life span, who in the past would have passed away (The, 2009).

However, this increase in medical prowess has challenged the patients' perception of their involvement and control in end of life decisions. The debate around the autonomy of the patient at their end of life has increased recently. Terry Pratchett, an author who is diagnosed with dementia, publicly advocates in favour of assisted death (www.terrypratchett.co.uk). Debby Purdy who has Multiple Sclerosis, clarified the law on relatives assisting in suicide. In the Gilderdale legal case a mother was found not guilty of murdering her daughter, who had ME and asked her mother to help her die (The Guardian, 8th February, 2010). There are numerous reports of people of all ages travelling to Zurich to end their life with the help of the Swiss organisation Dignitas, which assists people with their suicide.

When Kelleher, Chambers and Corcoran (1998) reviewed 51 countries regarding their end of life practices; they found that 22 permitted passive euthanasia and non-voluntary passive euthanasia. In 44 countries Physician Assisted Suicide was a crime.

The Netherlands (since 2001) is the only country where there is a legal framework for assisted suicide and euthanasia. In Belgium euthanasia is regulated since 2002 (Lemiengre, 2008) and in Switzerland assisted suicide is permitted if this is carried out on the request of the patient and if there are no benefits for the person assisting (Löfmark et al, 2008). Oregon State, USA has legislation for Physician Assisted Suicide (PAS) since 1994 (Farrenkopf & Bryan, 1999; Batavia, 2000; Sears & Stanton, 2001). A survey in the Netherlands over the period 1990-2001 showed that the requests for actual euthanasia or assisted suicide, after an initial increase, have remained stable at

2.2- 2.6% (8900 in 1990 and 9700 in 1995, Gordijn & Janssens, 2000). Physician assisted suicide is 0.1-0.2%.

Cohen et al (2006), used the European Values Studies which has national representative samples of 33 European Countries, to review several countries' acceptance of euthanasia. They found that certain countries (Netherlands, Denmark, France and Sweden) showed a higher acceptance, whilst Romania, Turkey, Malta were markedly lower. Weaker religious belief was the most important factor, however other socio-demographic differences emerged. Younger cohorts, people from non-manual social classes and higher educational levels tended to have higher acceptance levels. Similar patterns were found in an American General Social Survey study over the period between 1977 and 1988 (Caddell, & Newton, 1995).

Other studies have asked people who have a terminal condition their views. Rosenfeld (2000) found that 55% of people with a terminal condition would consider euthanasia if it was legalised, but only 6-8% had an active wish to die soon. Circirelli (1997) noted whilst 62% of people aged 18-85 approved of ending the lives of terminally ill people, only 49% of people over the age of 70 approved. Blank, Robinson, Prigerson and Schwartz (2001) presented 158 medically ill hospitalized older people (mean age 74.1) different hypothetical end of life scenarios. They found that 13-42% expressed an acceptance of euthanasia or PAS.

Rather than pain and other suffering, maintaining autonomy and control were the main motives used by people in favour of assisted suicide (Gordijn & Janssens, 2000;

Schroepfer et al, 2009). In contrast with the general public views, fewer members of the medical profession favour euthanasia (Teisseyre, Mullet & Sorum, 2005). In contrast with the general public, where in 63% found euthanasia acceptable, only 36% of the members of the medical profession favored euthanasia.

One qualitative study explored the personal, relational and cultural aspects of euthanasia, by interviewing older Israelis and their families (Liechtentritt and Rettig (2000). Younger and older informants attributed different meanings to the same form of assisted death, depending on who made the decisions. The younger generation was concerned with quality of life, while the older generation emphasized the transition and competence of dying. The phenomenological analysis of the fundamental meaning of assisted suicide revealed 3 factors: different forms of assisted death, different decision makers and particular cultural aspects. The core of the above factors according to Leichtentritt and Rettig was the wish to protect oneself and as a means of solving the dialectic conflictual dimensions with significant others.

4. The hypotheses

As this is a qualitative study, there are no hypotheses as such, but the following research questions will be addressed:

- What discourses do older people draw on when they talk about assisted suicide and euthanasia?
- How have those discourses come to be culturally available and what effects do they have?

- Can through the discourse of older people insight be gained about possible power relationships that might exist in society in relation to older people and their views on end of life decisions?

5. Participants: recruitment methods, age, gender, exclusion/inclusion criteria

Recruitment is envisaged to take place via the participant panel of the School of Psychology, Bangor University; University of the Third Age, WI and/or opportunistic recruitment, using snowballing sampling. Within a qualitative research framework, purposive sampling is an accepted way of recruiting.

Lay people, 65 and older, who at time of the interview have not been diagnosed with a physical health condition, which is terminal, and are not receiving treatment for a terminal condition, are eligible for participation in the study. They should not be receiving treatment for any mental health problems at the time of the interview.

In a qualitative methodology, depending on the quality of the interview, up to 12 participants will be required to take part in the study.

The choice to recruit older people who are **not** terminally ill is twofold.

1. Existing research does include the views of (usually older) people who are physically unwell or whose condition is terminal.
2. The ethical issues in carrying out research with people, who are physically unwell, are more complex. Their cognitive function could have been affected by to the treatment, pain or the condition itself and could also hinder obtaining informed consent.

6. Research design

The study will employ a qualitative methodology to address the research question, as a quantitative approach will, in its choice of questionnaires or vignettes, have made a range of assumptions about factors influencing attitudes and decisions.

Discourse analysis with a Foucauldian focus will be used to answer the research question. Applying a methodology based on Foucauldian discourse analysis, will look at how language works, not only to produce meaning but also look at though particular kinds of objects and subjects upon whom and through which particular relations of power are realised (Graham, 2005). The production of meaning enables statements to present a particular view of the world and prepares the ground for the practices that derive from them, i.e. legislation and debates around euthanasia and assisted suicide (Hook, 2001).

7. Procedures employed

Participants will be interviewed using a semi-structured interview. The interview questions will refer to the participants understanding of the terminology used, their views on the current debate, their personal experience of death and dying, and who or what would influence their end of life decisions. The interview schedule will be further developed and reviewed in conjunction with the supervisor after each interview (Potter & Hepburn, 2005).

8. Measures employed

As such no measures will be used. Demographic data will be collected regarding age, gender, marital status, education and profession. Other information will be obtained as part of the interview, e.g. experience of death and dying, religious beliefs.

9. Qualifications of the investigators to use the measures (Where working with children or vulnerable adults, please include information on investigators' CRB disclosures here.)

Drs. Carolien Lamers

Doctorandus in Social Gerontology, University of Nijmegen, The Netherlands.

Statement of Equivalence, British Psychological Society

Dr. Rebecca Williams

Doctorate in Clinical Psychology, University of Hull

10. Venue for investigation

The interviews can be conducted in an office at the School of Psychology, Bangor University or another venue convenient for the participants.

11. Estimated start date and duration of the study (N.B. If you know that the research is likely to continue for more than three years, please indicate this here).

Depending on the approval date from the ethics committee, September 2010 is the intended starting date, with 31 December 2011 as the date for completion.

12. Data analysis

Discourse analysis with a Foucauldian focus will be employed to answer the research question. Initially the transcripts will be read in detail, while listening to the tapes. Themes will be identified in the first transcript and will be used to inform analysis of the next transcript. Each interview will be read to elicit new themes and to further confirm or elaborate on themes that emerged in previous transcripts, paying particular attention to any similarities or differences. In the Foucauldian aspect of the analysis the themes will be reviewed to see how through the discourses around euthanasia and assisted suicide, these are constrained, facilitated or limited.

13. Potential offence/distress to participants

Euthanasia and assisted suicide are emotive topics, because of the existential and criminal nature of the debate. Although the participants are not facing an imminent death, due to their age they will all have experienced bereavements and the interview could trigger traumatic experiences and memories. The proximity to their own death could also create anticipatory anxiety.

The Primary Investigator (PI) is a qualified clinical psychologist, who routinely works with clients who are emotionally distressed as part of her NHS post. If the participant indicated that he/ she would like further support and advice, information about service options like the GP, primary care counseling services or Cruse can be discussed and made available to them. (See Debriefing letter below)

14. Procedures to ensure confidentiality and data protection

Prospective participants will receive an information sheet via the organizations mentioned under question five, setting out the focus and nature of the study, with the

invitation to contact the PI for further information. Interested participants can then be contacted by phone or e-mail with more information and if they agree to take part in the study, formal written consent will be obtained (see below). The participant will be informed that at any time during the interview they can withdraw their consent and the interview will be terminated and any paperwork destroyed and recordings removed.

Basic demographic information (age, gender, marital status, education and profession) will be collected on paper. Interviews will be recorded using a digital recorder and will be transcribed onto the PI password protected laptop. The participants' demographic details will be kept in a separate file on this laptop, linking these details to the specific transcripts. The paper data and transcripts will be kept in a locked filing cabinet at the North Wales Clinical Psychology Programme, until the thesis has successfully been defended. At such time, the data and transcripts will be destroyed and permanently deleted in the time specified by Bangor University policy and data protection legislation.

Participants will be informed that either the PI or a typist, will transcribe the interviews. The typist will adhere to same confidentiality rules as the PI.

Any excerpts used in the thesis, will not be attributable to any participant in particular, thus ensuring anonymity. Pseudonyms will be used.

Participants will be informed that the study has obtained ethical approval from the School of Psychology Ethics Committee, Bangor University.

15. *How consent is to be obtained (see BPS Guidelines and ensure consent forms are expressed bilingually where appropriate. The University has its own Welsh translations facilities on extension 2036)

Consent will be confirmed either by receiving a completed consent form by post or via e-mail. If the consent form is received by e-mail, the participant will require to sign the form at the time of the interview. The participants will be reminded at the time of the interview about the content of the consent form. As the participants are all considered to have mental capacity, consent to take part in the study should not raise any concerns.

The Welsh translation of the information sheet and consent form will be obtained when ethics approval has been granted.

16. Information for participants (provide actual consent forms and information sheets) including if appropriate, the summary of the study that will appear on SONA to inform participants about the study. N.B. This should be a brief factual description of the study and what participants will be required to do.

The advert, information sheet, consent form and debriefing in both English and Welsh can be found pp. 157-168.

17. Approval of relevant professionals (e.g., GPs, Consultants, Teachers, parents etc.)

N/A

18. Payment to: participants, investigators, departments/institutions

The participants will be reimbursed for travel expenses if they need to travel to the appointment for the interview. This will either be cost incurred using public transport or mileage as per Bangor University standard rate.

19. Equipment required and its availability

The North Wales Clinical Psychology Programme will provide stationary and recording equipment.

20. If students will be engaged a project involving children, vulnerable adults, one of the neurology patient panels or the psychiatric patient panel, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)

N/A

21. If students will be engaged in a project involving use of MRI or TMS, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)

N/A

22. What arrangements are you making to give feedback to participants?

The responsibility is yours to provide it, not participants' to request it.

Ethics Application

Participants can indicate on the consent and contact form if they wish to receive a summary of the findings. This will be send to participant at the provided address once the project has been successfully completed.

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Advert (English)

COLEG IECHYD A GWYDDORAU YMDDYGIAD
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SCHOOL OF PSYCHOLOGY



Euthanasia and Assisted Suicide

**Are you over 65?
Tell us your views about these end-of-life choices.**

We are interested to hear how people over the age of 65 engage with the debate around euthanasia and assisted suicide. The voice of this group is rarely heard or reported in the current discussions. The study will be carried out via interviews.

If you want more information about the study conducted at Bangor University, contact Carolien Lamers either by phone 01248 388068 or by e-mail c.lamers@bangor.ac.uk.

*This study has been approved by
Bangor University Ethics committee.*

Advert Cymraeg

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Ewthanasia a hunanladdiad â chymorth

A ydych dros 65 oed?

Dywedwch eich barn am y penderfyniadau hyn ar ddiwedd bywyd.

Rydym eisiau gwybod barn pobl dros 65 oed am ewthanasia a hunanladdiad â chymorth. Ni chaiff lais y grŵp hwn ei glywed yn aml mewn trafodaethau o'r fath ar hyn o bryd. Caiff yr ymchwil ei wneud trwy gynnal cyfweiliadau.

Os hoffech ragor o wybodaeth am yr astudiaeth hon a gynhelir ym Mhrifysgol Bangor, cysylltwch â Carolien Lamers naill ai ar y ffôn 01248 388068 neu trwy e-bost c.lamers@bangor.ac.uk.

Cymeradwywyd yr astudiaeth hon gan bwyllgor moeseg Prifysgol Bangor.

Information sheet (English)

COLEG IECHYD A GWYDDORAU YMDDYGIAD
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Information sheet

Study Title:

Older Adults and the euthanasia/ assisted suicide debate.

Project Team

Drs. Carolien Lamers
Dr. Rebecca Williams

Invitation to participate

We are interested to hear how older adults engage with the debate around euthanasia and assisted suicide. The voice of this group is rarely heard or reported in the current discussions.

Please read this information sheet carefully and if there are any issues that are unclear or if you feel that you need more information about the study please contact Drs. Carolien Lamers on the contact number or via e-mail at the end of this information sheet. Carolien will contact you with more information and an opportunity to discuss the study. Please take time to decide whether you wish to take part in the study.

Purpose of the study

The debate in the UK is ongoing regarding euthanasia and assisted suicide. We are interested in hearing the voice of older adults in the UK and want to understand how they position themselves in this debate. Studies have been carried out with people who are physically unwell, health care professionals and the general population, but there is limited knowledge about the position of older adults in general and in the UK in particular.

Who can take part in the study?

We are looking for adults over the age of 65, who are currently not receiving treatment for a life threatening or terminal condition and are not receiving treatment for mental health problems.

Regrettably as the main researcher is a Welsh learner, the interviews will need to be conducted through the medium of English.

Do I have to take part in the study?

It is up to you to decide whether you wish to take part in the study. If you decide to take part and change your mind, you can withdraw at any point from the study, without giving a reason. All information you have provided up to that point, will be removed and destroyed.

If you do decide to take part, please sign one consent form and return this either in the pre-paid envelope provided (**no stamp is required**) or reply by e-mail to c.lamers@bangor.ac.uk and attach the consent form.

What will happen if I do decide to take part?

If you decide to take part in the study:

1. Please return the consent form in the pre-paid envelope provided or by e-mail.
2. You will be contacted by Carolien to arrange a convenient time and place for an interview. This can either take place at Bangor University or another location. Any costs that you incur for travelling will be reimbursed.
3. You will be asked to provide general demographic information.
4. The interview is likely to take between 30 minutes and 90 minutes.
5. The interview will be recorded.

What are the potential risks in taking part in the study?

We do not anticipate any potential risks in taking part in the study. However, euthanasia and assisted suicide are emotive topics and the interview could remind you of experiences and memories that are related to death and dying. You can of course end the interview at any time without giving an explanation. If you feel that you would like further support, information about relevant agencies can be discussed with you.

All information that you provide will be strictly confidential. The tapes will be transcribed by either Carolien or a typist, who is adhering to strict confidentiality rules. The paperwork and tapes will be kept in a locked cabinet and the transcripts on a password protected laptop. The interview will be wiped of the recorder and the laptop and any paperwork destroyed in line with data protection legislation and Bangor University policies. Your interview will be used in the write up the study but you will not be named and any other identifying factors will be anonymized.

What will happen to the results of the research study?

When the study is completed, a written summary will be sent to everyone who took part in the study and who indicated that they would like feedback regarding the study. As this study forms part of an educational qualification, a copy of the study will be kept at Bangor University. The study may be published and presented at different conferences. Can I stress again that you will not be identifiable in any way in any of these.

Who has reviewed the study?

This research has been reviewed and approved by the Ethics Committee of the School of Psychology, Bangor University.

Contact details for further information:

Drs. Carolien Lamers
Clinical Psychologist
School of Psychology

University of Wales, Bangor,
Adeilad Brigantia, Bangor, Gwynedd, LL57 2AS
Tel: 01248 388068 Email.lamers@bangor.ac.uk

If you have any complaints about how this study is conducted, please address these to the person below:

Prof. Oliver Turnbull
Head of School
School of Psychology
Bangor University,
Adeilad Brigantia,
Penrallt Road,
Bangor, Gwynedd, LL57 2AS

Thank you very much for taking the time to read this information sheet and for considering taking part in the study.

Information sheet (Cymraeg)

COLEG IECHYD A GWYDDORAU YMDDYGIAD
COLLEGE OF HEALTH & BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY



Taflen wybodaeth

Teitl yr astudiaeth:

Oedolion hŷn â'r ddadl am ewthanasia/hunanladdiad â chymorth

Tîm y project:

Drs Carolien Lamers

Dr Rebecca Williams

Gwahoddiad i gymryd rhan

Rydym eisiau gwybod barn oedolion hŷn am ewthanasia a hunanladdiad â chymorth. Ni chaiff lais y grŵp hwn ei glywed yn aml mewn trafodaethau o'r fath ar hyn o bryd.

Darllenwch y daflen wybodaeth hon yn ofalus ac os oes rhywbeth yn aneglur neu os hoffech ragor o wybodaeth am yr astudiaeth, cysylltwch â Drs Carolien Lamers trwy'r rhif ffôn neu'r cyfeiriad e-bost sydd ar waelod y daflen wybodaeth hon. Bydd Carolien yn cysylltu â chi gyda rhagor o wybodaeth ac i roi cyfle i chi drafod yr astudiaeth. Cymerwch eich amser cyn penderfynu a ydych am gymryd rhan yn yr astudiaeth.

Pwrpas yr astudiaeth

Ar hyn o bryd, mae trafodaeth yn mynd rhagddi yn y DU am ewthanasia a hunanladdiad â chymorth. Rydym eisiau clywed barn oedolion hŷn yn y DU a deall eu safbwynt am y ddadl. Mae astudiaethau wedi eu cynnal gyda phobl gyda salwch corfforol, gweithiwyf gofal iechyd a'r boblogaeth gyffredin, ond ychydig o wybodaeth sydd ar gael am safbwynt oedolion hŷn yn gyffredinol, ac yn y DU yn benodol.

Pwy all gymryd rhan yn yr astudiaeth?

Rydym yn chwilio am oedolion dros 65 oed, nad ydynt ar hyn o bryd yn cael triniaeth am gyflwr terfynol nac yn cael triniaeth am gyflwr sy'n bygwth bywyd nac yn cael triniaeth am broblemau iechyd meddwl.

Yn anffodus gan mai dysgwr yw'r prif ymchwilydd, bydd rhaid cynnal y cyfweiliadau yn Saesneg.

A oes rhaid i mi gymryd rhan yn yr astudiaeth?

Chi sydd i benderfynu a ydych am gymryd rhan yn yr astudiaeth. Os ydych yn penderfynu cymryd rhan ac yna yn newid eich meddwl, gallwch dynnu'n ôl o'r astudiaeth ar unrhyw adeg heb roi rheswm. Caiff yr holl wybodaeth amdanoch ei hepgor o'r astudiaeth a'i dinistrio.

Os penderfynwch gymryd rhan, llenwch y ffurflen gydsynio a'i hanfon yn ôl naill ai yn yr amlen a ddarparwyd (**nid oes angen stamp**) neu trwy e-bost at c.lamers@bangor.ac.uk.

Beth fydd yn digwydd os byddaf yn penderfynu cymryd rhan?

Os byddwch yn penderfynu cymryd rhan yn yr astudiaeth:

1. Anfonwch y ffurflen gydsynio yn yr amlen a ddarparwyd neu trwy e-bost.
2. Bydd Carolien yn cysylltu â chi i drefnu amser a lle cyfleus i gynnal y cyfweiliad. Gellir cynnal y cyfweiliad ym Mhrifysgol Bangor neu mewn lleoliad arall. Byddwn yn ad-dalu unrhyw gostau teithio i chi.
3. Byddwn yn gofyn i chi roi gwybodaeth ddemograffig gyffredinol i ni.
4. Mae'r cyfweiliad yn debygol o bara rhwng hanner awr ac awr a hanner.
5. Byddwn yn recordio'r cyfweiliad.

Beth yw'r risgiau posib o gymryd rhan yn yr astudiaeth?

Nid ydym yn rhagweld bod unrhyw risgiau posib o gymryd rhan yn yr astudiaeth. Fodd bynnag, mae ewthanasia a hunanladdiad â chymorth yn bynciau emosiynol iawn a gallai'r cyfweiliad eich atgoffa am brofiadau a materion yn ymwneud â marwolaeth a marw. Wrth gwrs, gallwch ddod â'r cyfweiliad i ben ar unrhyw adeg heb roi rheswm. Os byddwch yn teimlo eich bod angen rhagor o gymorth, gallwn roi gwybodaeth i chi am asiantaethau perthnasol.

Bydd yr holl wybodaeth a gawn gennych yn hollol gyfrinachol. Caiff y tapiau eu trawsgrifio naill ai gan Carolien neu gan deipyddes fydd yn cadw at reolau cyfrinachedd caeth. Caiff y gwaith papur a'r tapiau eu cadw dan glo mewn cwpwrdd a chaiff y trawsgrifiadau eu cadw mewn gliniadur wedi ei ddiogelu gan gyfrinair. Caiff y cyfweiliad ei ddileu o'r peiriant recordio a'r gliniadur a chaiff unrhyw waith papur ei ddinistrio yn unol â deddfwriaeth gwarchod data a pholisïau Prifysgol Bangor. Caiff eich cyfweiliad ei ddefnyddio yn yr adroddiad am yr astudiaeth ond ni chewch eich enwi ac ni fydd modd eich adnabod yn yr adroddiad.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth ymchwil?

Ar ddiwedd yr astudiaeth, byddwn yn anfon crynodeb ysgrifenedig at bawb a gymerodd ran yn yr astudiaeth a nododd eu bod eisiau derbyn crynodeb. Gan fod yr astudiaeth hon yn mynd tuag at gymhwyster addysgol, caiff copi o'r astudiaeth ei gadw ym Mhrifysgol Bangor. Mae'n bosib y caiff yr astudiaeth ei chyhoeddi a'i chyflwyno mewn cynadleddau amrywiol. Ni fydd modd eich adnabod mewn unrhyw un ohonynt.

Pwy sydd wedi adolygu'r astudiaeth?

Mae'r ymchwil wedi ei adolygu a'i gymeradwyo gan bwyllgor moeseg Ysgol Seicoleg Prifysgol Bangor.

I gael gwybodaeth bellach, cysylltwch â:

Drs Carolien Lamers
Seicolegydd Clinigol
Ysgol Seicoleg
Prifysgol Bangor

Adeilad Brigantia, Bangor, Gwynedd LL57 2AS
Ffôn: 01248 388068 E-bost: c.lamers@bangor.ac.uk

Os oes gennych unrhyw gwynion am y ffordd y cynhaliwyd yr astudiaeth hon, a wnewch chi eu hanfon at:

Yr Athro Oliver Turnbull
Pennaeth yr Ysgol
Ysgol Seicoleg
Prifysgol Bangor
Adeilad Brigantia
Ffordd Penrallt
Bangor, Gwynedd, LL57 2AS

Diolch yn fawr am roi o'ch amser i ddarllen y daflen wybodaeth hon, ac am ystyried cymryd rhan yn yr astudiaeth.

Consent form (English)

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COLLEGE OF HEALTH & BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY



**Consent and Contact Form
Older Adults and the Euthanasia/ assisted suicide debate**

Have you read all the information in the Information Sheet? YES / NO

Have you had the opportunity to ask questions
and discuss the study? YES / NO

Have you received reasonable answers to you questions? YES / NO

Are you willing to take part in the study,
and for the information you give us to be used in this research? YES /NO

Are you aware that you can change your mind at any time? YES / NO

Are you willing for the interview to be recorded
and for the information to be used in the research? YES / NO

Are you aware that the interview might be transcribed
by somebody other than the interviewer? YES/ NO

Would you like a summary of the study? YES/ NO

Signature:..... Date:.....

Name in Capitals:.....

Address:.....
.....
.....

Telephone Number:.....

E-mail Address:

Consent form (Cymraeg)

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**Ffurflen gydsynio a gwybodaeth gysylltu
Oedolion hŷn â'r ddadl am ewthanasia/hunanladdiad â chymorth**

- A ydych wedi darllen yr holl wybodaeth ar y daflen wybodaeth? YDW/NAC
- A ydych wedi cael cyfle i ofyn cwestiynau
a thrafod yr astudiaeth? YDW/NAC
- A ydych wedi cael atebion rhesymol i'ch holl gwestiynau? YDW/NAC
- A ydych yn fodlon cymryd rhan yn yr astudiaeth ac yn fodlon i ni
ddefnyddio'r wybodaeth a gawn gennych yn yr ymchwil? YDW/NAC
- A ydych yn gwybod y cewch newid eich meddwl ar unrhyw adeg? YDW/NAC
- A ydych yn fodlon i ni recordio'r cyfweiliad ac yn fodlon i ni
ddefnyddio'r wybodaeth yn yr ymchwil? YDW/NAC
- A ydych yn gwybod ei fod yn bosib y bydd rhywun heblaw
am y cyfweilydd yn trawsgrifio'r cyfweiliad? YDW/NAC
- A ydych eisiau cael crynodeb o'r astudiaeth? YDW/NAC

Llofnod:.....
Dyddiad:.....

Enw mewn priflythrennau:

Cyfeiriad:
.....
.....
.....

Rhif ffôn:

Cyfeiriad e-bost:

Debriefing Letter (English)

COLEG IECHYD A GWYDDORAU YMDDYGIAD
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Older adults and the euthanasia/ assisted suicide debate Guidance for further advice and support

Euthanasia and assisted suicide are emotive topics and the interview could have reminded you of experiences and issues that are related to death and dying. Usually it is family and friends, who know you and your life story well, who can be a really good sounding board for sharing this with.

If you feel that you would like further advice and support, can I suggest the following services and agencies to contact.

- **Your GP.**

He or she is likely to be familiar with your particular personal history and experiences. The GP can provide advice, reassurance and can discuss with you other support or interventions that might be helpful.

- **The GP Counseling services.**

One of the services that the GP can refer you to are Primary Care Counselors, who work in your local practice. They provide time limited counseling sessions to explore issues further.

- **Cruse Bereavement Care.**

Cruse is national charity that offers free and confidential help to people who have experienced loss. They provide information on their website:

<http://www.crusebereavementcare.org.uk/>

They can be contacted by e-mail: helpline@cruse.org.uk or on the daytime helpline 0844 477 9400

- **Religious or Spiritual leaders.**

If you have a religious faith or spiritual life, consider contacting your leader in your faith for further guidance.

Thank you very much for taking part in this study.

Carolien Lamers

School of Psychology
Bangor University
01248-388068
c.lamers@bangor.ac.uk

Debriefing letter (Cymraeg)

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Oedolion hŷn â'r ddadl am ewthanasia/hunanladdiad â chymorth Gwybodaeth am gyngor a chefnogaeth ychwanegol

Mae ewthanasia a hunanladdiad â chymorth yn bynciau emosiynol iawn a gallai'r cyfweiliad fod wedi eich atgoffa am brofiadau a materion yn ymwneud â marwolaeth a marw. Gall eich ffrindiau a'ch teulu sy'n eich adnabod yn dda ac yn gwybod eich hanes fod o gymorth i chi drafod i hyn.

Os ydych yn teimlo bod arnoch angen rhagor o gyngor a chefnogaeth, rwy'n awgrymu eich bod yn cysylltu â'r gwasanaethau a'r asiantaethau canlynol:

- **Eich meddyg teulu.**

Mae eich meddyg teulu'n debygol o fod yn gyfarwydd â'ch hanes a'ch profiadau personol. Gall roi cyngor a gall dawelu eich meddwl a thrafod cefnogaeth neu ymyriadau eraill a allai fod o gymorth i chi.

- **Gwasanaethau cwnsela meddygon teulu.**

Gall eich meddyg teulu eich cyfeirio at gwnsleriaid gofal sylfaenol, sy'n gweithio yn eich practis lleol. Gallent drefnu sesiynau cwnsela i chi allu trafod ymhellach.

- **Cruse Bereavement Care.**

Elusen genedlaethol yw Cruse sy'n cynnig cymorth cyfrinachol ac am ddim i bobl sydd wedi cael profedigaeth. Ceir gwybodaeth ar eu gwefan:

[<http://www.crusebereavementcare.org.uk/>](http://www.crusebereavementcare.org.uk/)

Gallwch gysylltu â hwy trwy e-bost: helpline@cruse.org.uk neu trwy ffonio eu llinell gymorth yn ystod y dydd

0844 477 9400

- **Arweinwyr crefyddol neu ysbrydol.**

Os oes gennych ffydd grefyddol neu fywyd ysbrydol, ystyriwch gysylltu ag arweinydd eich ffydd am ragor o gymorth.

Diolch yn fawr iawn am gymryd rhan yn yr astudiaeth hon.

Carolien Lamers

Ysgol Seicoleg
Prifysgol Bangor
01248-388068
c.lamers@bangor.ac.uk

Ethics Committee Letter of Approval

By e-mail.

2nd November 2010

Dear Carolien,

1655-A1928 Amendment to How and where do older lay people position themselves in the euthanasia and assisted suicide debate? A qualitative exploration.

Your research proposal number 1655-A1928 has been reviewed by the School of Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of five years from this date.

Ethical approval is granted for the study as it was explicitly described in the application.

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Governance approval is granted for the study as it was explicitly described in the application and we are happy to confirm that this study is now covered by the University's indemnity policy.

If any new researchers join the study, or any changes are made to the way the study is funded, or changes that alter the risks associated with the study, then please submit an amendment form to the committee.

Yours sincerely

Everil McQuarrie

Appendices

Appendix 1. Table of papers regarding Advance Decisions (ADs)

The papers are grouped by research design. Where appropriate subheadings are being used.

* The majority of the studies were carried out in the USA, where the Patient Self Determination Act was introduced in 1990. This Act requires all health care providers to discuss ADs with their patients. This occurs in a context where health care resources are not free for all USA residents, unlike the UK. The transferability of the findings to other countries and health care structures needs to be cautious.

(Systematic) Reviews

Study	N	Age	Sample	Nature of study	Findings	Quality
Bravo et al. (2008)	12.692	Average age 70, range 44-90	55 studies from USA*, Canada and Australia 18 RCT 27 single group 10 other Half respondents outpatients Most educated in single session	Systematic review Effectiveness of interventions to promote AD among older adults	<ul style="list-style-type: none"> • 43% completion of ADs in single arm studies • RCT pooled odds ratio 4.0 • All comparative studies pooled odds ratio 2.6 	<p>Papers included from peer and non-peer reviewed journals, with a range of research designs. Quality of the research therefore variable.</p> <p>Effect sizes calculated per research design, which provides more relevant information.</p>

Study	N	Age	Sample	Nature of study	Findings	Quality
Jezewski et al. (2007)	No data provided but sample sizes of studies reported as appropriate for statistical analysis used	14 studies samples are 50 years and older 10 studies samples are 16 years and older 1 study did not report demographic information	25 studies from USA* and Canada 14 RCT/ control group 3 quasi experimental 8 pre-experimental Mainly female and white	Systematic literature review Effectiveness of intervention to increase uptake of ADs, either didactic or interactive	<ul style="list-style-type: none"> Post intervention rates didactic: 0-34%, interactive: 23-71% Didactic interventions less successful, than offering the option of asking questions and discussion 	<p>Mixed range of study designs, which were analysed using type of interventions, rather than research design.</p> <p>Wide range of interventions reviewed, with varying levels of intensity, communication and expertise, but for analysis purposes grouped into didactic and interactive only.</p> <p>Outcome of having AD defined in different ways and thus not clear if the interventions resulted in completion of usable and legal documents.</p>
Patel, Sinuff & Cook (2004)	3206	Average age reported per individual studies, ranging 53-84 years.	9 RCT studies Countries where research conducted not reported Gender reported per individual study, ranging from 43-73% female	Systematic review Educational interventions impact on AD completion rates for non-terminally ill older people	<ul style="list-style-type: none"> Varying odds ratios depending on the rigor of the methodology, varying from 2.42 to 28.68 Education may increase completion rates of ADs 	<p>Lack of homogeneity in samples: with acute and chronic health conditions and in either home, or hospital setting. Interventions ranges in intensity, including didactic and interactive.</p> <p>Presence of a control group in all studies making conclusions about the effect of an intervention stronger.</p>

Study	N	Age	Sample	Nature of study	Findings	Quality
Shalowitz et al. (2006)	2595 surrogate-patient pairs	Not provided	16 studies Countries where research conducted not reported Terminally and chronically ill, outpatients and convenience sample	Systematic review Accuracy of surrogate decisions	<ul style="list-style-type: none"> • Surrogates predict patient treatment preferences with 68% accuracy • Accuracy was not affected by type of relationship nor discussions 	All studies used hypothetical scenarios, not clear how this translates to accuracy in real life decisions.
Lemiengre et al. (2007)	N/A	N/A	19 studies from USA*, Canada, The Netherlands and Belgium Written institutional ethics policies on medical end-of-life decisions	Literature review Prevalence, content, communication, or implementation of written institutional ethics policies	<ul style="list-style-type: none"> • Majority DNR policies • Dutch and Belgium: pain and symptom control and euthanasia and assisted suicide • Focus on procedural and technical aspects rather than ethical principles • Scare number of studies looking at implementation of policies 	The studies are from countries where people have some control over end-of-life decisions either via AD or eu/as. The absence of policies from other countries is interesting, perhaps accessing these non-English policies is required. Useful note that there is little research into the implementation of policies.

Appendix 1

Study	N	Age	Sample	Nature of study	Findings	Quality
Neimeyer et al. (2004)	N/A	N/A	N/A	Literature review on death anxiety, fear, threat, acceptance, attitudes	Following on from Feifel's early efforts, five areas are reviewed: death attitudes in the elderly, the relationship of death concerns to physical health, death anxiety of medical and non-medical caregivers, relationship between fear of death and psychopathology, association between religiosity and apprehension of death and terror management.	Good overview of research in the area of Thanatology

Retrospective studies

Study	N	Age	Sample	Nature of study	Findings	Quality
Abarshi et al. (2009)	637	44% aged 41-80 years 53% over 80 years	Netherlands 48% female	Mortality follow-back study	<ul style="list-style-type: none"> • 46% of patients had GP's who were not aware of preferred place of death (POD) • 88% preferred to die in a private or care home, 10% in a hospice or palliative care unit and 2% in hospital • 80% with known POD died there 	Reflection of Dutch health system and role of the GP. Transferability to other health care systems is unclear.
Dobbins (2007)	160	Average age 81	USA* Deceased patients in community hospital 55% female 99.4% white	Retrospective study Evaluate AD and effect on care decisions	<ul style="list-style-type: none"> • 20% had AD in notes • 67% had informal AD guidance in notes • No relationship between treatment and wishes in either formal or informal ADs 	Mainly white sample, impact of race known from other studies. People from non-white background, less likely to complete AD. Retrospectively establishing adherence to ADs can be problematic as medical notes or death certificate do not always provide the relevant information.

Appendix 1

Study	N	Age	Sample	Nature of study	Findings	Quality
Hammes et al. (2010)	940 440 in 1995/6 500 in 2007/8	Average age 80, range 20-108	USA* 54% female Ethnicity not reported, but commented on mainly white catchment population	Retrospective study Impact of ADs on care Using medical records and death certificates	<ul style="list-style-type: none"> • With intensive interventions, the prevalence and availability of ADs in medical records improved (85% vs 90%) • Adherence to the ADs in 1995/6 98% and in 2007/8 99.5% 	<p>Retrospectively establishing adherence to ADs can be problematic as medical notes or death certificate do not always provide the relevant information.</p> <p>Mainly white sample.</p> <p>Follow up study helpful to review change in practice.</p>
Hickman et al. (2010)	1711	Average age 85, SD 8	USA* Nursing home residents Living and deceased 70% female 88% white	Survey study	<ul style="list-style-type: none"> • No difference in symptom assessment or management between people with or without AD 	<p>Telephone survey, no 'hard' evidence of existing symptoms, health conditions etc.</p> <p>Predominantly female and white sample.</p>

Study	N	Age	Sample	Nature of study	Findings	Quality
Silveira et al. (2010)	3746	Average 80 All over 60 Age surrogates not reported 49% adult children, 33% spouses	USA* 53% female 86% white	Survey Surrogates of deceased older people	<ul style="list-style-type: none"> • If people had AD, they were more likely to have asked for limited care • Without AD more likely to receive more aggressive interventions • Patients requesting limited care (83%) care or requested comfort (97%) were likely to receive care consistent with their wishes 	<p>Recall bias possible when surrogate were asked about adherence to AD, due to time lapse and possible role they played in decision making themselves. Desired congruence could be influencing recall.</p> <p>Predominantly white sample, but more equal gender distribution.</p>
Ganz et al. (2006)	363	Average age 62, SD 21	Israel Admission to ICU unit 43% female	Retrospective study	<ul style="list-style-type: none"> • 69% had treatment withheld in contrast with 30-38% in other European areas • 36% of Israeli families were involved in end of life discussions 	<p>Israeli sample</p> <p>Comparison with other countries make it clear that end-of-life decisions are not purely medical decisions but they reflect health care provision, cultural and religious differences.</p>

Surveys/ questionnaires

Communication and attitudes towards Advance Decisions

Study	N	Age	Sample	Nature of study	Findings	Quality
Ali (1996)	162	59% aged 60-69 41% older than 70	USA* Non-hospitalized 65% female 94% white	Survey	<ul style="list-style-type: none"> • 27% had AD • 96% wants to participate in end of life decisions • 64% doctor had not mentioned it • 31% not sure about quality care received 	Recruitment process unclear. Predominately white sample.
Campbell et al. (2007)	118	Average age 73, SD 8	USA* Community 81% female 86% white	Descriptive	<ul style="list-style-type: none"> • 63.9% had AD • Receiving information and attitude towards AD predicted completion • As health literacy increased, likelihood for completed AD reduced 	Predominately female and white sample. Useful attempt to develop model that predicts completion of ADs. Unexpected findings were that biological (age, gender, health) and cognition (education) factors are not included in the model.

Appendix 1

Study	N	Age	Sample	Nature of study	Findings	Quality
Carr & Khodyakov (2007)	3838	Range 64-65	USA* Community 55% female	Survey Part of longitudinal study	<ul style="list-style-type: none"> 75% had discussed their preferences with close kin, and over half had made formal arrangements Women were more likely to have had informal discussion, but less likely to have AD 	Large sample, but young old participants only, which could mean that findings are either age or cohort related. Longitudinal findings might help to elucidate this.
Porensky & Carpenter (2008)	170	Average age 75, SD 7	USA* Community 50% female 99% white	Questionnaires	<ul style="list-style-type: none"> Accuracy regarding knowledge of medical conditions and treatment varied between 59- 94% 	Predominately female and white sample. The health literacy questionnaire has not yet been validated or tested for reliability, although has face validity.

Study	N	Age	Sample	Nature of study	Findings	Quality
DeLuca Havens (2000)	210	Average age total sample 50, range 20-88 Executors (N=38) Average age 62, SD 15 Non executors (N=172) Average age 47, SD 14	USA* Systematic random community sample 44% female 99% white	Survey	<ul style="list-style-type: none"> • 18.1% had AD • Executors were older than non executors • No difference in preference to exercise personal autonomy between those with and without AD • People who completed AD were more religious than those not completed AD 	Predominately white sample. Attempts made to study factors identified in other studies as relevant to complete ADs, which can help to ascertain where a person is positioned on a change model continuum and which strategies might be useful to help to move towards a position where they complete an AD.
Hawkins et al. (2005)	337 older adults and their surrogates	Older adults: average age 73, SD 5 Surrogates: Average age 64, SD 13	USA* Community Older adults: 56% female Surrogates 68% female 92% white	Survey Part of longitudinal study	<ul style="list-style-type: none"> • Older people expressed more general wishes related to values and goals for care and allow the surrogates leeway in decision-making. 	Predominately white sample. Younger sample, but more balanced gender wise. Considering the findings that non-white people are less likely to have ADs, there is a need for more studies with a wider range of ethnic groups and educational backgrounds.

Appendix 1

Study	N	Age	Sample	Nature of study	Findings	Quality
Hopp (2000)	520	All aged over 70 63% aged 70-80	USA* Community 63% female 90% white	Survey	<ul style="list-style-type: none"> • White people more likely to have AD than African Americans and those with less than high school education • Although 95% indicate they had someone to make health care decisions for them, only 49% had spoken with this person about their preferences 	Predominantly white sample. Considering the findings that non-white people are less likely to have ADs, there is a need for more studies with a wider range of ethnic groups and educational backgrounds.

Appendix 1

Study	N	Age	Sample	Nature of study	Findings	Quality
Mezey et al. (2000)	1016	Average age 52, range 18-94	USA* Discharged patients, white, black and Hispanic 54% white	Survey	<ul style="list-style-type: none"> • 20.4% have AD. • Of those having an AD, 90.3% are English speaking. • 37% thought they had to fill it out. • 92% 'wanted to make up own mind' • 21% Wanted family to decide • 30% doctor will do what is right • Reasons for not having AD: 12% religion and all must be done to preserve life 	Large sample, with mix in ethnic backgrounds, addressing some of the limitations of the samples in other studies.

Study	N	Age	Sample	Nature of study	Findings	Quality
Salmond & David (2005)	80	Range 51-70	USA* Hospitalised patients 69% female 75% Black American 11% white	Survey Descriptive correlational study	<ul style="list-style-type: none"> • 40% unable to describe AD despite routinely provided education • 26% completed AD, wanting control over decisions and avoiding overtreatment • 38% wanted family to decide • Completion rates lower in non-white • No differences in attitudes towards AD in completers and non-completers 	<p>Predominately non-white sample, addressing some of the sample biases in other studies.</p> <p>The sample is an inpatient group who are likely to be physically unwell. Other studies (e.g. Winter et al, 2009) indicate that health status impacts on health wishes. A British sample (Seymour et al, 2005) felt that they would rather not be asked about their end-of-life wishes when physically unwell.</p>

Appendix 1

Study	N	Age	Sample	Nature of study	Findings	Quality
Schickedanz et al. (2009)	143	Average age 61, SD 9	USA* Community 77% female 23% white	Descriptive Interviews, quantitative and content analysis	<ul style="list-style-type: none"> • 90% did not have an AD • 46% not discussed wishes with family, 80% not with their doctor • 43% of those who had not contemplated ADs, preferred to leave health in God's hands 	Predominately non-white sample, addressing some of the sample biases in other studies.

People's end-of-life wishes

Study	N	Age	Sample	Nature of study	Findings	Quality
Decker & Reed (2005)	176	Average age 74, range 60-98	USA* Community 90% white 74% female	Questionnaires	<ul style="list-style-type: none"> • People generally preferred less aggressive end of life treatment • People with higher moral reasoning (those considering both the autonomous and social domains of reasoning) requested more aggressive treatments. 	<p>Predominantly female and white sample.</p> <p>Helpful introduction to consider the psychological concept of moral reasoning to understand end-of life decision-making.</p>

Appendix 1

Study	N	Age	Sample	Nature of study	Findings	Quality
Rietjens et al. (2005)	1388	Range 20-93	Netherlands Community 59% female	Survey	<ul style="list-style-type: none"> • One third preferred quality over length of life • One third preferred length of life over quality • One third does not know • Older people more likely to prefer quality of life • If quality of life preferred, more likely to have AD 	Large Dutch sample, covering the life span.

Appendix 1

Study	N	Age	Sample	Nature of study	Findings	Quality
Winter et al. (2009)	230	Average age 77, range 69-95	USA* Community 63% female 57% white	Interviews and case scenarios	<ul style="list-style-type: none"> • Race strong predictor of years of desired life in range of case scenarios • Race difference caused by religion or distrust of health service • Relative acceptability of poor health prospects to sicker people and acceptance of aggressive interventions. Supportive of Prospect Theory 	<p>Balanced sample regarding gender and ethnicity.</p> <p>Needs longitudinal data to support the initial evidence for the Prospect theory.</p>

Study	N	Age	Sample	Nature of study	Findings	Quality
Rao et al. (2008)	44	Average age 71, SD 5.1 range 65-84	USA* Hindu, English speaking, community	Semi structured interview and questionnaires	<ul style="list-style-type: none"> • 20% knew about AD • 6% had living will • Family central in decision making • Negative feelings regarding life prolonging or – sustaining treatments • Positive regarding health care system, doctors 	<p>Small homogenous sample.</p> <p>Although a study carried out in the USA, it provides evidence for the impact of a different culture and value base on end-of-life decisions, despite being embedded in an American culture and health system.</p>
Sudore et al. (2010)	205	Average age 61, SD 8	USA* Chronically ill out patients 53% female 25% white	Descriptive study Case scenarios	<ul style="list-style-type: none"> • 45% were unsure about their decision in a hypothetical scenario with a certain negative outcome • White people were more certain about their decision than non white, those with lower literacy and poor self rated health 	<p>The hypothetical nature of the case scenarios might not translate well to real life decisions, which are likely to be informed by other factors.</p> <p>A comparative study with healthy older people would examine the possible confounding factor of health status, as Winter et al (2009) found that current health status affected the acceptability of future health status.</p>

Appendix 1

Study	N	Age	Sample	Nature of study	Findings	Quality
Winter et al. (2010)	202	Average age 77, SD 6	USA* Community 72% female 66% white	Case scenarios	<ul style="list-style-type: none"> Modest correspondence (23% variance accounted for) between living will response and wishes for life sustaining treatment in specific scenarios points to poor performance of living wills. 	<p>Slightly skewed sample.</p> <p>The hypothetical nature of the case scenarios might not translate well to real life decisions, which are likely to be informed by other factors.</p> <p>Highlights the difficulty with the language used in ADs, and the person's health literacy.</p>

Older people and surrogate decision makers

Study	N	Age	Sample	Nature of study	Findings	Quality
Fagerlin et al. (2001)	361 older people and their surrogates	Older Adults: average age 74 Surrogates: average age 63 Duration of relationship mean 48 years	Older people 56% female 93% white Surrogates 68% female 92 white	Correlational study	<ul style="list-style-type: none"> • 46% had AD • Surrogates wanting more treatment • Surrogates' predictions were related to own preferences 	Predominantly white sample. Useful to have a comparison study of students and their parents (N=60), to control for possible effects of aging in terms of forgetting. This makes the findings more robust.
Sansone & Phillips (1995)	168 residents 153 surrogates	Older adults: average age 83, range 65-98 Surrogates: Age not reported 70% children	USA* Nursing and residential homes 79% female	Correlational study using case scenarios	<ul style="list-style-type: none"> • 24% had AD • Concordance rates between older person and surrogate of a range of health scenarios varied between 28-73% 	The hypothetical nature of the case scenarios might not translate well to real life decisions, which are likely to be informed by other factors.

Professionals' views regarding Advance Decisions

Study	N	Age	Sample	Nature of study	Findings	Quality
Torke et al. (2009)	281 physicians	Not reported	USA*	Survey	<ul style="list-style-type: none"> • 73% had made a best interest decision month preceding survey, but had only a prior relationship with 19% • When surrogate contactable (79%), conflict was rare (5%) 	<p>Recall bias possible.</p> <p>Providing valuable insight into the perspective of the other player in end-of life decisions.</p>
Schiff et al. (2006)	842 geriatricians	Not reported	UK	Survey	<ul style="list-style-type: none"> • 56% had cared for somebody with an AD • 39% had changed treatment • 78% felt decisions were made easier • Concerns were expressed regarding patients changing their mind, lack of understanding, or completed under duress. 	<p>UK sample, echoing some of the issues raised in Torke et al's American sample.</p> <p>Recall bias possible.</p> <p>Majority of geriatricians had never designed an AD with patient. How is physicians' sense of autonomy affected by this, when asked to execute an AD they were not involved in designing? Does this impact on their perceptions of ADs?</p>

Repeated measures studies

Study	N	Age	Sample	Nature of study	Findings	Quality
Ditto et al. (2003)	332	Average age 75, SD 5 range 67-96	USA* Community 57% female 92% white	Repeated measures 12 and 24 months using case scenarios	<ul style="list-style-type: none"> • Stability levels for end of life preferences over 2 year period 0.76 • Stability varied across scenarios • Those with an AD are more stable in their preferences • With psychological and physical health deteriorating, wish for life sustaining treatment decreases 	<p>Predominantly white sample.</p> <p>The hypothetical nature of the case scenarios might not translate well to real life decisions, which are likely to be informed by other factors.</p> <p>The nuances of some of the answers are lost in the analysis when answers are collapsed in a dichotomy.</p>

Study	N	Age	Sample	Nature of study	Findings	Quality
Sharman et al. (2008)	332 older adults 329 surrogates	Average age 75, SD 5 range 67-96 Average age 62, SD 13 range 29-88	USA* Community 57% female 67% female	Repeated measures 12 months using case scenarios	<ul style="list-style-type: none"> Older adults falsely remembered 75% of their original end of life decisions, were the same as the current decisions Surrogates falsely thought that 86% of older adults' decisions had not changed 	The hypothetical nature of the case scenarios might not translate well to real life decisions, which are likely to be informed by other factors.
Sulmasy et al. (2007)	147	Average age 62, SD 13	USA* Terminally ill patients 37% female 65% white	Repeated measures 3-6 months	<ul style="list-style-type: none"> Preference for shared decision making Relied on loved ones for substituted decision and best interest decisions by physicians Over time views regarding loved ones remains the same, but prefer less reliance on physicians. 	Good use of visual stimuli to illustrate the choice options. Impact of attrition rates on findings due to high mortality in sample is not clear. However, they do use a population averaging technique.

Intervention studies/RCT to increase completion rates of Advance Decisions

Study	N	Age	Sample	Nature of study	Findings	Quality
Detering et al. (2010)	309	80 years and older	Australia Medical inpatients and their families 154 intervention 155 control	Randomized control trial Providing advance care planning vs. care as normal	<ul style="list-style-type: none"> • In the intervention group, 86% of those who died in 6 months after the interventions, had expressed wishes and adhered to, with only 30% in control group • Family members of people who died in intervention group reported significant less stress, anxiety and depression than those of the people in the control group 	Australian sample Single centre study, which might not generalize to other sites, as this could have been a reflection of clinical practice, culture and commitment in the trial site.

Study	N	Age	Sample	Nature of study	Findings	Quality
Golden et al. (2009)	530	Average age 80, SD 8 range 63-100	USA* Community 70% female	Intervention study	<ul style="list-style-type: none"> Reported reasons for not completing AD was reluctance to consider own mortality After intervention (reminder by case manager), 1.6% proceeded to obtain an AD 	<p>No control group, hence difficult to attribute change to intervention alone</p> <p>Intervention not very powerful, as it only involved a reminder to consider completing an AD.</p>
Hamel et al. (2002)	74	Average 72, SD 8 range 54-93 82% over 65	Canada Community 37 intervention 58% female 37 control 78% female	Posttest-only Experimental control and randomized group design	<ul style="list-style-type: none"> No difference in the number of ADs completed in either group (12 in intervention and 7 in control group) No differences between intervention and control on completion and discussion of AD Reluctance to consider mortality and deteriorating health as reason for non completion 	<p>Canadian sample</p> <p>Intervention not very powerful, as it only involved an additional phone call and information following an education session.</p>

Appendix 1

Study	N	Age	Sample	Nature of study	Findings	Quality
Lawrence (2008)	Evercare 11.775 MDS 12.246	Over 65 years	USA*	Secondary analysis and comparison design of interventions under two health care models	<ul style="list-style-type: none"> One care model that used nurse practitioners had a higher rate of AD completion rate, regardless of gender, race or education 	The explanation given for the difference in outcome between the two models is not clear. Moreover, one practitioner has a higher completion rate than others. The possibility of coercion was not considered by the authors.
Molloy et al. (2000)	116	77	Canada Community Veterans 96% male	Intervention study Education provided by counsellors	<ul style="list-style-type: none"> 82% receive education 24% refused to complete an AD after being educated 36% of the sample that received education completed AD 	Canadian sample Predominantly male sample, due to selection of veterans. No control group, hence difficult to attribute change to intervention alone.

Appendix 1

Study	N	Age	Sample	Nature of study	Findings	Quality
Support, 1995	9105 Phase 1 4301 Phase 2 Intervention 2652 Control 2152	Range 18-103	USA* Five hospitals	Intervention study Nurses enhancing communication with patients	<ul style="list-style-type: none"> Despite high level intervention to i.e. increase communication, enhance ADs; no improvements were noted in communication, end of care received etc. 	<p>Large study, now almost 20 years old.</p> <p>The intervention was carried out by nurses, who tend not to be involved in en-of-life decision making, despite being more likely to have a more intense relationship with the patients. The intervention was potentially carried out by the ‘wrong’ people.</p>

Qualitative research

Study	N	Age	Sample	Nature of study	Findings	Quality
Bradley, et al. (2010)	10 surgeons	Not reported	USA* 20% female	Semi structured interviews Grounded theory	<ul style="list-style-type: none"> • See AD as framework for discussion • Frustration about disconnect between reality and written ADs • Felt conflicted between adherence to AD and desire for cure 	Predominantly male sample. Surgeons tend to have less intensive relationships with patients, which might be required when considering the execution of ADs. Yet at the same time the actions of surgeons can have a big impact on the possible outcome for a patient.
Dea Moore & Sherman (1999)	20	Range 58-78	USA* Community 55% white 80% female	Semi structured interviews Analysis based on 'reasoned action'	<ul style="list-style-type: none"> • Higher religiosity and belief in God's will increased completion of AD • Discussions about death and dying more comfortable if people have faith • Eight participants reported reticence in the children to discuss end of life 	Methodology chosen is based on 'reasoned actions', which tends to be more suitable to quantitative research.

Appendix 1

Study	N	Age	Sample	Nature of study	Findings	Quality
Kelner (1995)	38	39% aged 65-75 45% aged 76-85 16% aged 85 plus	Canada Hospitalised patients 66% female	Interviews Comparison and content	<ul style="list-style-type: none"> 71% were activist, favoured withholding and withdrawing 29% were delegators preferred to delegate to others: physician, God, fate 	Canadian sample. Psychological concepts introduced to explain variability in attitudes to AD. It would be helpful to repeat the study with community sample, as people might be influenced by active health concerns.
Malcomson & Bisbee, (2007)	20	Range 64-94	USA* Community and assisted living 75% female 90% white	Four focus groups Content analysis	<ul style="list-style-type: none"> Concerns not to burden others motivate to have AD Older people assume that their preferences are known, even without explicit communication 	Predominately female and white sample. Focus groups encourage naturally occurring conversations, reflecting current thinking amongst participants. Could have considered discourse analysis.

Study	N	Age	Sample	Nature of study	Findings	Quality
Munn et al. (2008)	11 older adults 19 relatives 35 carers	Not reported	USA* Residential and nursing homes 64% female residents 90% female staff and family 82% white residents and family 45% white staff	Ten homogenous focus groups Grounded theory	<ul style="list-style-type: none"> • Desire for good death: symptom management, preparation, closure, spirituality, dignity • Normalcy of dying in care • Role of relationships in provision and receipt of care 	The possible impact of non-white staff caring for mainly white residents was not considered in the findings.
Rosenfeld et al. (2000)	21	Average 83, range 72-92	USA* Community 95% white 81% female At least one or more chronic health conditions	Qualitative interviews IPA	<ul style="list-style-type: none"> • 81% had AD • Concern about the outcome of treatment rather than treatment itself • Decision making granted to physicians for their knowledge and family to secure person's interest 	Predominantly female and white sample. Possibly unrepresentative sample with a high percentage of people who have an AD.

Study	N	Age	Sample	Nature of study	Findings	Quality
Sessanna (2008)	12	72 All over 65	USA* Community 50% female 100% white	Individual semi-structured interviews One focus group N=7 Grounded Theory	<ul style="list-style-type: none"> Emerging concepts: connection, contributing, supporting and believing 	White sample only, but with equal gender distribution. Interesting use of a focus group as a verification method to check on accuracy of the findings.
Seymour et al. (2004)	32	4 under 60 20 aged 65-74 7 aged 75-87	UK Community groups 71% female 81% white	8 Focus groups Content analysis	<ul style="list-style-type: none"> Interdependence between older person and family, own wishes considered in context of others 	UK study. Predominantly female and white sample. Unique insight into the views of a group of British older people. Focus groups encourage naturally occurring conversations, reflecting current thinking amongst participants. Could have considered discourse analysis.
Schikendanz et al. (2009)	143	Average age 61, SD 9	USA* Medical patients 54% female 23% white	Mixed methodology Thematic content analysis	<ul style="list-style-type: none"> Identified barriers to AD completion: contemplation, relationship concerns for family and friends, time constraints for clinicians, AD documentation 	Mixed ethnic sample and equal distribution re gender. Mixed methodology provided opportunity to elaborate on answers, thus obtaining richer data.

Study	N	Age	Sample	Nature of study	Findings	Quality
Robinson (2011)	9 dyads	Average age 69, range 55-78	Canada Pairs of newly diagnosed cancer patient and significant others	Structured interviews Constant comparative analysis	<ul style="list-style-type: none"> Deciding on an AD is developing a shared understanding of ones preference with loved ones Older people wanted their significant other to make their own decisions rather than solely relying on their stated preferences 	Canadian sample. An analysis of real life negotiations and end-of-life decision making, which outcomes challenge the assumption that people strive for autonomy at the end of life.
Vig et al. (2006)	50 surrogates	Average age 63, range 40-84	USA* 90% female 90% white	Semi structured interviews Thematic content analysis	<p>Surrogates rely on</p> <ul style="list-style-type: none"> conversations (66%) documents (10%) shared experience (16%) own value and preferences (28%) social network (18%) 	Predominantly female and white sample. The sample was unrepresentative as they had already received extensive training in ADs in another study and are described as experienced surrogate decision makers-makers.

Theoretical papers / Opinions/ Professional body guidance

Study	N	Age	Sample	Nature of study	Findings	Quality
Candib (2002)	N/A	N/A	USA*	Theoretical paper	Reflection of impact of cultural values on end of life choices, with emphasis on autonomy being a western value.	Useful paper that challenges western concepts considered relevant in ADs, and puts them in a historical context.
Cantor (1998)	N/A	N/A	USA*	Theoretical Paper	Reflections on the dignity and the utilising value profile that might assist people to define what is intolerable suffering	Enriches current thinking around ADs, by moving away from wishes regarding treatments to wishes that are consistent with the values of a person.
General Medical Council (2010)	N/A	N/A	UK	Professional Body Guidance	Treatment and care towards the end-of-life: good practice in decision making	Mainly related to Mental Capacity Act (2005). Limited reflections on ethical dilemmas.
BPS (2007)	N/A	N/A	UK	Professional Body Guidance	Guidance on determining the best interest of adults who lack the capacity to make a decision (or decisions) for themselves [England and Wales].	Useful guidance in assessment of capacity, usually in relation to mental health. Very few examples related to physical health decisions or AD issues.
BPS (2011)	N/A	N/A	UK	Professional Body Guidance	The role of psychology in end-of-life care.	Describes range of roles for psychology.

Study	N	Age	Sample	Nature of study	Findings	Quality
Mezey et al. (1996)	N/A	N/A	USA*	Professional education and advice	Setting out the nature of ADs and the role nurses can play in facilitating the decision making process	Emphasis on role of nurses in the decision making process, who tend to know the patient better but hitherto are not formally included in the decision making process.
Rich (1998)	N/A	N/A	USA*	Opinion	The competent person who wrote the AD is not the same person as the incompetent person and the former should not dictate the care of the latter	Philosophical arguments, illustrated with an example of a person with an AD who has developed dementia. Preconceived ideas about the abilities of a person with dementia miss out aspects of communication relevant to the consideration of the usefulness of the AD.
Wass (2004)	N/A	N/A	USA*	Opinion	Identifies needs to enhance education of medical profession regarding death and dying, requiring integration of knowledge and personal engagement	Identifies lack of personal development issues regarding death and dying in the training of medics in USA.
Schicktan z et al. (2010)	N/A	N/A	Germany Israël	Comparative study of ethics statements	Comparison of discourse around end-of-life decisions between Germany and Israël, using statements of ethics committees	Despite shared historical background in terms of genocide, religious factors appear more important in the ethical considerations.

Appendix 2.1 Participant's demographic information

Participant nr.....

Age	
Marital status	
Gender	M / F
Education/ employment	
Health status	
Faith/ religion/ spiritual life	
Recent bereavements	
Consent sheet reviewed and agreed	

Appendix 2.2 Interview schedule

Three areas were identified for the interview to capture several aspects of the debate around euthanasia and assisted suicide (eu/as):

1. externalising to establish the knowledge and understanding of the terms used,
2. personalising to access the language used by the participant to ascertain development of ideas and personal meaning and
3. specifying for those in favour of eu/as motivators, dilemmas and circumstances under which they would consider eu/as.

Introduction

I would like to talk to you about assisted suicide and euthanasia and see how older people speak about these two end-of-life options.

Externalizing

It was decided not to define the terms in advance as set by the literature as the language used by the participants might reveal their knowledge about the concepts and add to the understanding of the power relationships expressed in the discourse. The definitions given by the participants in the two pilot interviews revealed variable knowledge and understanding about the acts of eu/as, the context. It was therefore decided to refrain from presenting the definitions and let the participants create the reality.

- 1) Can you tell me what in your words euthanasia means?
- 2) Can you tell me in your words what assisted suicide means?
- 3) How are they the same, different?

Personalising/ Explicating

- 1) What does euthanasia assisted suicide mean to you as a person?
- 2) When/ what triggered did you first start thinking about eu/as?
- 3) How have your ideas developed over time, what has influenced your thinking on this?
- 4) How do you feel about legalising eu/as?

Specifying

- 1) How/ what does life need to be like, for you to consider eu/as?
- 2) Under what circumstances would you consider eu/as?
- 3) What would you do about it?
- 4) How would this be different for/ in case of.....depending on the nature of the conversation?

Closing questions

- 1) Is there anything that you feel we have not discussed that you feel is relevant?
- 2) Are there any areas that you feel that are just too difficult to discuss?

Appendix 2.3

Sample transcript interview and analysis

	Transcript interview with Liz	Themes and discourses	Language, omissions, differences, alternatives	Evidence of Foucauldian concepts
CL	Certainly relevant to		Lots of you know and checking out?	
Liz	You'll have to shut me up then	Do others shut you up?	No voice, voiceless	Powerless
CL	No. No no Please talk, that's what I need you to do, the least I talk the better (laugh)	I am inviting her to talk		
	<i>Section removed</i>			
Liz	Unfortunately, most of the people in that, are for yes and do, we haven't got anybody that is on the other side you know, it that's what makes it more interesting, presumably you are getting people from both sides	Regret Separation, conflict Silence from those opposing Wanting to hear the other side. Are there 2 or more sides?	What does yes and do mean? 'The other side': euphemism for death Sounds argumentative Not interesting to hear her side? Do I have the attraction that will get others who are against eu/as to talk to me?	
	<i>Section removed</i>			
Liz	Yes, yeh, but I think well I have a friend who is dead against it and she just will not enter into any conversation about it at all. Ehm, I said to her 'you know we'd	Need to engage Like difference, others Fear, attached to beliefs, you change	Dead against: Give your life for it? Not enter: not open to Feel rather than	Closed response, no dialogue. Power relation between those against, which is current law, and thus hold the power, but not

	like people at the group, that feel as you do'. 'No, you won't change my mind'. 'No, I don't want to change your mind but you know, it would be nice for us to hear your points of view' but anyway	my mind, can I do that?	think Hear rather than be persuaded	wanting to talk as scared their mind might be changed What power do you think I have?
CL	Mmm. Your friend could not be persuaded to be interviewed cause I'm open to which angle anyway		Over-power her?	
Liz	I've told her again, I've had another try today, this morning actually and I said 'going to the university this afternoon' and eh 'oh oh what about?', cause she comes I told her 'ohhh' (Shudders) you know	Repeated request	Repeats that she has repeated her request: tried hard to please me Physical disgust: emotive topic	
	<i>Section removed</i>			
Liz	Yeah, euthanasia is a way of ending life, ehm, without pain, and just sleeping away, isn't it? It so, eh, like you would with a dog or a cat or I say that's euthanasia, isn't it?	Peaceful death Away to where? Animals, later on as well	There are more ways of ending life Confusion, checking out Put animals down	Knowledge patchy/uncertain Animals death is decided by humans, done to them
CL	Hmm			
Liz	Ehm as against suicide, tj, not sure about that, but eh, you know. Euthanasia is usually, ehm, given when you know there	Is not sure what eu is. What is real and what isn't?	Who is for and against what? Given, by whom, who does 'it' Who decides no hope. Is it	Powers of some to give eu Others know about hope, have knowledge

	is there is no real hope, eh, just to, you know, go away nicely and quietly ehhe (laughs)	Go where?	obvious? No mess, neat, tidy	
CL	Ok			
Liz	When the time is there and not after	Timing	Who determines time?	
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CL	If you could define that for me, what do you?			
Liz	Yeah, just define it, assisted suicide is if somebody gives you the means, eh, to finish your life eh or assist you physically, I would've thought. Ehm, that's how I would see that.	Some uncertainty And incorrect	Just define it: not easy Where is a statement about 'what I want'?	Incorrect knowledge Somebody helps you to do it, depend on others
CL	Ehm and how then are euthanasia and assisted suicide the same?			
Liz	No, definitely not.		Strength of reply	
CL	No? how are they different then?			
Liz	How are they different? (..) Thsj I don't really know really actually, now you think you know, now you say really ehm cause the end is the same but eh (...) eh (.) I don't know. Personally, ehm I don't know whether I would be strong enough as a person to take that tablet, but if I'd left it ehm, no I	Does it matter what the journey is, if the destination is the same? For whom does it matter? Strong/ brave vs weak? For what?	Despite previous strong response, can not articulate difference Determined enough? Personally vs society?	

	don't know really (..) ehm. (.) I really can't answer that question how			
CL	So if you left it, what does that mean, if you left it cause you move your hand out like that. What would			
Liz	Yeah, left it, I suppose I would just sleep away and not really. I made the decision, that's what I mean, that's definitely what I want to do, ehm, when the time is right. I suppose really I am asking somebody else to make the final decision for me, where as with assisted I suppose it would be the same then, wouldn't it really. Hadn't really thought about it. You think of, I think what you would prefer	Not getting the distinction I decide What I want at the right time Deciding yourself or somebody else?	Sleep and death, are they the same? Speaks with certainty, but then not clear about the impact	Confused, knowledge lacking Diffusing responsibility, watering down the I want, to asking somebody else to decide
CL	What would you prefer?			
Liz	Euthanasia, (laughs) definitely		But she does not know. Although very definite, use of superlatives	Strong preference, without reasoning, not based on knowledge but emotion
CL	And euthanasia is where somebody else?			
Liz	Yes I suppose so yes yes			
CL	Somebody else does what?			
Liz	Well, I'd like to think that either, eh, to be	Refers to living will, rather than	Others control what happens.	Confusion

	given an injection or for treatment to be just with held. So, I just want an injection I suppose really, that's what I would like yes .	eu/as	Decides herself for somebody else to do something	Who controls? Can we tell others or do they do to us?
CL	And for somebody else to do it rather than for you to have to take the pill			
Liz	I don't think I could do it you know	Doubt about self and actions to be taken	Not liking as, as not able to do it What can you do?	Do I have power at all? Or is not deciding exercising power?
CL	You don't think you could			
Liz	I don't know whether I could or not	Confused		
CL	Tell me a bit more about that, just mither away about			
Liz	Yes yeah eh. Well, I mean I always think it takes tremendous courage to eh to commit suicide, doesn't it. Eh, maybe if I was desperate enough can cause I'm reasonably strong but I can't see myself. How I think about it when I, you know, go ahead with this is yes I would need to have a heart attack or a stroke or cancer or something like that, something will happen and I don't want to be in, you know, a nursing home for	Do you need to be strong to commit (dedicate) to eu/as? Future fears Growing old, with risks of becoming dependent. Not referring to pain and suffering, but requiring care in care-home setting Come back from what?	Bravery? Desperate: not rational Go ahead: commitment Reasonably: ratio comes in again No human way of eating Uncertainty about final decisions	Loss of control, but wanting to control end of life, helpless. Sense that others control as they need to take responsibility, Who are these others? Others know how to feed through a tube: knowledge, but also they decide what I eat, when, how much.

	<p>years, being fed by a tube or anything. I just like to, if there's any chance that I am not going to be able to lead eh a reasonable life, I I don't want to come back, I want to just go (.) and eh so I suppose really and yet this is the one reason why I think it is so difficult to get it through because you're asking somebody else then to take responsibility, aren't you, <i>and people change after relatives die, they change their ideas so</i> (..) (laughs). I used to be a health care assistant ehm with elderly people</p>	<p>Incorrect fact</p> <p>Sense of fluctuation</p>	<p>Narrow opportunity</p>	
CL	Oh all right			
Liz	<p>And I saw some elderly people and they argued like cat and dog and she'd curse him or he'd curse her and everything and when they died, they were the most wonderful husband and wife that ever lived, you know, and eh, it's a big responsibility to have somebody to take, isn't? tjs tjs and eh, <i>I don't know</i>. Did that answer your question? Doesn't really, does it? Tsj</p>	<p>Animal analogy</p> <p>Transient views</p>	<p>Witnessing others</p> <p>Can you trust yourself? Views are coloured and not necessarily the 'truth'</p>	<p>Gaze</p> <p>Who can be trusted to make the right judgment?</p>

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Liz	Well yes, I suppose so, I'm assuming I would just be able to say, you know, I've had enough and that's it. I mean, we have the forms to put in and I, you put in there ehm, but if I'm not conscious I can't take that but there is a space on the form where you can fill in how long, you know, if you are unconscious, how long you want to be kept alive for and things and	Doubt and uncertainty Living wills Not sure about the active step Need to be conscious, rational	Disjointed language Kept alive by whom or what? Attempt to control end of life via advance decision Others keep you alive, outside your control	I decide, I have the power But depend on other people/ physicians/ family/ machinery/ medicine?
	<i>Section removed</i>			
Liz	Yes, yeah ehm, (.) eh, yeah I don't (.) I mean I love life, I'm, you know, I'd like to live forever if I could at the moment, but eh I I I am frightened I suppose, of what what I could be like when you look around and you see and I think 'ach, I wouldn't want to be like that', I'd rather just go as you would with an animal really. When you know everything starts to break down, <i>just go, it's time</i>	Like life at it is Fear of dying/living not death, not wanting to die What is the animal analogy? Somebody else decides for the animal Acceptance of the end Acknowledge deterioration	Watching and witnessing others Projection? Just go? As if it was easy	Who watches her while others decide? Not wanting to be seen like that
CL	You've described it as a reasonable life, what would be a reasonable life?			

Liz	<p>What would be a reasonable life be? Well, certainly would like to be able to feed myself and to be able to sort of have eh. (.) I'm not afraid of dementia, eh, more afraid I suppose really of arthritis or strokes or. I wouldn't, eh (.) <i>so I mean. What's a reasonable life? Yes I think, I don't, I think so long as I could look after myself yes, or if I had a partner, between us, you know, we could look after ourselves. I'd like to as soon as my independence is eroded, I think I'd like to be</i></p>	<p>What would it be like to be fed? Maintain basic self care, just with family and not outside agency. Being with loved ones, connected Not a minute later or sooner</p>	<p>Quiet voice around what is a reasonable life? Disjointed speech Eroded: slow process, leaves you thin, disappearing</p>	<p>Doing things independently. Having control Who decides on a reasonable life if you are not conscious?</p>
CL	<p>Hmm, again a really tricky questions. What does independence mean? What? Can you define it?</p>			
Liz	<p>Be able to look after myself and not eh to have to rely on other people for ehm, normal functions and eh, to be able to prepare food however simple just to be able to look after myself really.</p>	<p>Do things yourself Rely on others for euthanasia and AD</p>	<p>Simple? Not asking for much. Can they take up space and ask for more?</p>	<p>Reliance on others, look after self, rather than others looking at/ after me</p>
CL	<p>So independence is something to do with doing things yourself?</p>			
	<p><i>Section removed</i></p>			
Liz	<p>Eh Yeah ehm (...)</p>	<p>Change of mind?</p>	<p>Do I know?</p>	<p>Feeling</p>

	<p>Yes, I suppose so, <i>I don't know</i> eh, I would like to, yes I prefer to do it myself. Eh, I suppose if my partner and I were there, and we would have to muddle through together that would be ok. But I wouldn't like just to be stuck in a wheelchair in a house on my own and not be able to do anything. That would be, you know, that's time to go</p>	<p>Muddle, chaos, not clear</p> <p>Sense of stagnation, isolation,</p> <p>Natural ending of life</p>	<p>Prefer? Would she tolerate others doing it? Ambivalence</p> <p>In <i>a</i> house rather than <i>my</i> house. Could it be a care home?</p>	<p>helplessness, powerless</p> <p>Out of people's gaze</p>
CL	Mmm			
Liz	<p>I mean at the moment I'd feel if I couldn't drive my car, I think I would be going (laughs). I like to be off and</p>	<p>Drive: set the direction of the journey: autonomy</p>	<p>Sense of freedom</p> <p>Like to be off, like a quick death</p>	<p>Choice, decision, powerful</p>
CL	<p>So you think there might be different sorts of levels of, now it feels like driving your car would be</p>			
Liz	<p>Yes, as ye I mean, that's true as you get older you do do that, don't you? You, you, you, your horizons shorten and your expectancy shortens, doesn't it? I suppose as the moment I've got nothing wrong with me. I'm fit I'm healthy ehm (.) You know, you, it's difficult to visualise</p>	<p>Foreseeing problems in the future</p> <p>Preparing for old age</p> <p>Not damaged yet. Could be step like way? Requires imagination</p>	<p>Setting sun</p> <p>Lower expectancies: lower acceptance?</p> <p>Not think it through? Visual like the arts</p>	

	really how what stage you would feel that you'd had enough.			
CL	Mmm mmm			
Liz	When you fit and healthy eh. Because, you know, maybe next week I will have something wrong and I won't be able to use this arm but I would probably manage by using that arm (laughs)	No idea what will happen tomorrow Time scale, reference to timing issues	There is always another way Fit and healthy: falling to bits: pick up the pieces:	Health is uncontrollable
CL	Mmm			
Liz	And eh so, that's a difficult question really ehm. (.) It's funny this really this, isn't? Cause I've always been quite definite about what I want, but you you're putting questions in my mind now you see. No, it's good, it's good that you do ehm (..) So, I don't know (laughs)	Not sure about self	Doubting, confused and conflicts	Observing self and own processes of thinking and responding
CL	Hmm, so what I'm hearing you say is that now this might be a reasonable life but you don't know in time to come			
	<i>Section removed</i>			
Liz	So, that makes me feel a bit like a control freak doesn't it (Laughs) But, I suppose yeah ehm (..)		Who controls? Freak negative association with madness	Is controlling own life not acceptable? Who can control our life?
CL	Can you say a bit more about that?			
Liz	Sorry?			

CL	Can you say a bit more about control freak?			
Liz	Well yes, I want to be in absolute control and when I'm not, that's it, time to go, I suppose, so it's independence, I suppose, isn't really	Is control the same as being independent?	Absolute, not a bit Absolute control=power	Loss of power/control, life not worth living
CL	Mmm			
Liz	Quite quite free, I don't like to be tied down at all, options open	Image of care in nursing home? Change mind?	Slavery Imprisoned	Controlled, no escaping can be checked as people know where you are
	<i>Section removed</i>			
CL	Mmm, If I'm right, because euthanasia and assisted suicide are not legalised in this country, I'm assuming you can't specify that on the living will? The living will will only			
Liz	No, you can only say that you want treatment withdrawn			
CL	Yeah yeah			
Liz	Ehm, that's what you can, yes, I don't know that'll ever have enough money to go to eh Holland, but I would say that I just hope that it comes here any way, hope it does.	Only the wealthy can afford it?	Luxury of choice	Money =Power
CL	Mmm			
Liz	<i>But it is a big thing cause you're asking other people to take the responsibility and</i>		Sounds troubled about that, also in relation to her father later on	Knowledge not correct Give and take of

	<p><i>eh (.), it would have to be a lot of things in place before you get people to do that, wouldn't you?</i> But eh, the suicide business, I'll just go back to that now, the thing that I really, really, really worries me and particularly that this Australian man, because I well, this is the only eh incident the only thing I know ehm, is that he would be quite happy to give me a pill to take when I felt ready and I just wonder, you know, there are times I wake up and I feel like death. You know, I feel ninety, never mind 68, and if you were suffering from depression or something, I mean it wouldn't make any difference to you cause you'd be gone and you wouldn't know, but whether you might be tempted to take this before. I, it worries me, worries me, <i>that</i></p>	<p>Is there money to be made from this? Colder, detached, transaction</p> <p>When are you ready? As you can feel like it but not be ready. Who would know? Impact on family</p> <p>Not trusting self Not rational, mad?</p> <p>It's all over.</p> <p>Playing with fire?</p>	<p>What is needed? What needs to be in place? Why so definite one minute and ambivalent the next</p> <p>He trusts me? But do I trust myself?</p> <p>Speaks in extremes, definitely and really x3 and then ambivalent</p> <p>The devil?</p>	<p>responsibility: negotiating power and control. Others exerting power on your behalf</p> <p>Not seen as human, but transaction</p> <p>Who has the power to decide? When given option, scared of trusting self and determining own destiny.</p>
	<p><i>Section removed</i></p>			
<p>Liz</p>	<p>I mean, I would be quite interested to hear him speak, I would like to hear him. If he came here, I would go because eh, it would</p>	<p>Dialogue?</p> <p>This man promotes assisted suicide,</p>	<p>and yet a slight hostile response</p>	

	be nice to hear his side of it and the points he put up really			
CL	Mmm, but the fact that somebody might feel low in mood			
	<i>Section removed</i>			
Liz	Mmm, ehm (...) well I suppose you think of people committing suicide, don't you, youngsters and things people doing that. I suppose, you wouldn't have a problem in older life with people committing suicide, well I wouldn't, I don't, I honestly don't think I would have the courage to take that pill. I don't know, I don't think I would. I don't think it's for me. Ehm (..) but usually suicides are people that are ending their life before there's any need to, isn't there? I think that's probably, it's probably like the word cancer, isn't it, you know, it's become a stigma, a bit of a difficult word.	<p>Suicide and youth Death and old age, suicide would be ok?</p> <p>Each to their own</p> <p>What is the need?</p> <p>Taboo</p>	<p>Think: fantasize</p> <p>Things? Others, not me</p> <p>Can old people commit suicide?</p> <p>Do you need courage for eu/as</p> <p>Keep quiet</p>	<p>As if objects</p> <p>We need to live and die according to how we are seen in society, internalising of discourses about young and older people</p>
CL	And euthanasia hasn't got that connotation for you?			
Liz	No, I don't think it has. It just puts to me just a peaceful slipping out. Where as suicide seems aggressive. (...)	Violence, force war and peace	<p>Non-event? fading</p> <p>Suicide rebellion of youth?</p>	

CL	The suicide seems to be something that you take yourself, how do you envisage euthanasia would be? How would that happen?			
Liz	Well, I would think that I would just sleep my way out of the world without pain and eh (..)	Sleep = dying?	Non event, not related to active act? Go to sleep every day, eu/as not every day	
CL	But some, I understood earlier on you said that somebody would need to take responsibility for that			
Liz	Yes, you'd have to would, I suppose you would, I mean, if I have a bad car accident or a heart attack or something like that, yes alright, they could let you, eh but if you had a stroke, a lot of the time, it's not that final, death isn't that final, is it? Eh, with a lot of things, cancer isn't that final, you usually have to go on till you get to the stage at the moment, ehm, eh, you know where you do die. I know they increase the drugs as you go along, but I think I would like it done before that stage came really	Sudden unexpected events, not requiring preparation Death isn't that final? What is? Not wanting to experience the final stage	They? Could let you. Who is they (Medics?) You have to go on, unclear who directs this going on <i>They</i> increase drugs	They decide, have the power See you as a road accident case Others judge but I would like to do it my self
CL	And what would you			

	like them to do?			
Liz	(..) Well, I don't mind how they do it but, well I do I suppose yeh. Well, either tablets or an injection or just eh (..) I suppose it, hh I wouldn't want to be, well I say I wouldn't want to be aware, but I would make the decision to do it so I eh (...) I hadn't really thought that I was conscious really, I just thought that I I I had this and they would produce it and that would be it and just go (laugh)	Sense of easyness	They do it? Who is they So implicit in language, no need to describe who they are Earlier on not wanting to take medication Not rational, but at emotional level decided	Passive recipient of intervention by medics? Not clear about taking responsibility
	<i>Section removed</i>			
CL	So, the idea of euthanasia is something about that you're not conscious or you're not aware of it?			
Liz	Well give, I suppose I would say you know I would be quite happy to say 'yes, this is the time, I want to go' and then eh, I mean, they can put gas on me or do what they want. I don't mind what they do really, so long as you just go (laughs) that's it I don't want to linggger , I don't want to linggger , ehm you know drifting in and out of	They can do what they want Reference to gas chambers, 2 nd WW Lengthy illness, said long stretched Impact on others	Not I go? I decide Handed over control/helpless Sense of uncontrollable process Being watched, unbearable waiting	And I oblige to what they want to do: subject? I give them permission, give certain aspect of power away Under their medical gaze Not being able to control either

	consciousness and every body stood around your bed and oeff. No, or or (.), you know, be sat in a chair and not be able to (.) function, no			
CL	Hmm			
Liz	Yes, ideally I would like to say right it's time and just have an injection and go		I determine, you do	
CL	Sorry for going on about this, I'm just trying to work out what would be the difference between you saying it's enough I don't want to linger. This is the time and somebody giving you a tablet that you need to take or somebody giving you an injection? What would be the difference in that?			
Liz	Yeah, no difference really, yes again I suppose I am not making myself clear. Yeah, I wouldn't mind somebody to give me a tablet to take that's not a problem but as far as I understood it, this chap was saying that he would give me the tablet now and I would take it when I was ready and I don't like that. I'd be quite happy to take a tablet, I'm quite happy to	No perceived difference in doing it yourself or being assisted. Not trusting self	Now she is willing to take a tablet? Others can decide when it is time for me to take the tablet Again confusion about the nature of the acts	Others have better knowledge about the 'me' than I do and I subject myself to their judgment and comply

	have an injection and to just go. So I suppose really that is assisted suicide then, isn't it really? It's not euthanasia, is it? Is it if you have an injection and you go is that the same as a tablet or			
	<i>Section removed</i>			
Liz	I suppose I am questioning again now, aren't I. Ehm, gosh, does everybody have food for thought like this (laughs) I feel now as if I haven't really thought through. I don't suppose I have really, I just feel	Slippery slope argument, as you have not thought it through and could be persuaded	Sense of being fraudulent, fake, cannot be relied on, can be ignored. Not been rational	
	<i>Section removed</i>			
Liz	Cause yes, if I'm happy to take a tablet that's assisted suicide, isn't really, so as I say, I don't mind really then	But not if it is suicide	Checking thing out, trying them for size	
CL	The sense I'm getting is what you're saying there is something different between having the tablets sitting there			
	<i>Section removed</i>			
Liz	No that is right, that's quite right, yeah yes. I would, I don't like the idea of him giving you tablets before you are ready, eh so eh	before I am ready.	He controls, before I am ready. Him giving. I do not want to think about it in advance and he does	Who controls who?

			Why you? And not I, concern for others?	
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CL	How, have you got any sense how you would know when you were ready?		Self knowledge	
Liz	(...) Well, I would eh (...) well I would know for sure I would know when I was ready but it's how others. I might not be able to communicate at that time, might I, so that is the whole idea of eh writing it down. Eh, I suppose really, I hope that [NAME] is there to say 'right, she has had enough, you know, we've got this here and its time to go', ehm (...). So that that would be, but if he is not here ehm (...), <i>gosh perhaps one of the children</i> (...) would. Cause I might not be, I mean that is the whole idea of put it in case you are not able to communicate when the time comes, isn't it really. I mean, it doesn't matter really, if it was six months early, makes no difference to me really, cause I'd be gone anyway. I don't have really once if	I know my self, but would not trust my self How do they know? Let others speak on my behalf Disturbed about considering it could be the kids. Kids vulnerable? What is impact on others with earlier death?	Another certainty Voiceless again, nobody will listen The only way to talk about this, is via the AD route, no other discourse available Quiet voice when mentioning kids Who is vulnerable Dividing line, related to being seen as a human? Functioning, rather than robot?	How can we become so doubtful about something that we can feel certain about? What is the mechanism that makes us doubt? Others know more about us?

	<p>you leave it ehm (..). You know, it's a (...) I am either here for six months or I'm not and eh (.) as far as I'm concerned, you know, if I can't function, well I don't want to be here, so eh (.) and so (.)</p>			
CL	<p>You mention your children and your partner. Have you discussed these things with your partner and your children?</p>			
Liz	<p>I've discussed it with eh, only loosely only loosely because I haven't actually made a paper work yet there on the purpose of doing but I have mentioned to the children that I was doing. My son, my middle, haven't mentioned to my eldest son. He's, I don't eh (..), I don't think he'll object but I ehm (.) I he would be 'ohh, I don't know why you'd want to do that' and that would be it. He is not the easiest people to speak to ehm, but my my middle son, I've mentioned it do him and he was dead against it. Ehm, but my daughter ehm (.) she sort of didn't</p>	<p>Unengaged, negating</p> <p>Creates strong emotions, that halt further discussion</p> <p>Limited engagement with children, vulnerable</p> <p>Generational/ gender issue</p>	<p>Tongue tight in talking about this, as difficult as it is in real life</p> <p>Not being tied down</p> <p>What is it about <i>dead</i> against, could you be <i>dead</i> for it?</p> <p>Women more open to the idea/ engagement?</p>	<p>There is no shared language to talk about this</p> <p>Others control the dialogue through their vulnerability. They exert the power despite being seen as vulnerable. How can you do that?</p>

	really like the idea ehm, but I but could see why I wanted to. And I must admit I suppose, we haven't eh (.) cause we took a copy of the last, what was it called, in Switzerland with Julie Walters			
CL	Oh yeah			
Liz	And I was going to show I wanted to show the children that, but I wanted to be with them really when I saw it so eh but I don't (..) eh. I think when I sit down and talk to my el my middle son ehm, you know he will be ok, my daughter will be ok and I know she will be ehm, she is quite ehm, (..) <i>I don't know how to describe it really</i> but I know she said 'I would have no compunction about putting you in a nursing home', you know sort of (laughs), I think she is quite, she hasn't taken started taking me out in the car to look for one yet. (laughs) But eh, so don't think she will be, I'm not quite sure about my eldest son and I suppose really, I am sort of hedging my bets a bit	Supporting children, seen as fragile, not open to it. Want family involved, rather than making up your mind. Needing support, approval of important others. Putting you in a home, not expecting to look after parent. As if parcel Kids fragile Gambling, risking No engagement, it is not there,	Be with them to support them when talking about eu/as but who will support them if you leave them after death/ eu/as Quiet voice again Need to make it lighter through laughter Not strong enough Death = Contaminated, dirty	Mixed messages, who leads and has the power? Family respond as if she is an object to be moved

	with him really. I think it is going to be difficult but not for the way that I think it will ehm 'oh, absolute rubbish' I eh think he'll just pass it off eh don't think he will want to talk about it somehow			
CL	What do you think makes it so difficult for the boys to talk about it? (..) More so perhaps than your daughter?			
Liz	Yes, ehm, (...) I'm their mum I suppose, I've always been there for them haven't I and eh, I think boys are closer to their mums, girls tend to be closer to their dads, aren't they, ehm, and I think (.) mum is always, although they might not discuss things, I think they it is their mother figure and mother does have a special place for the boys, the same as dads do with with girls really.	Connections Whose position is more powerful, mum or son? Kids not put her in a home yet? So who decides? Relationships, are they one way?	Not when you're dead Is loss of mother stronger felt?	Who has the final say?
CL	Hmm			
Liz	And know one other things, you know, [NAME] my daughter, we've always been able to talk about it ehm (.) anything. But the boys are a bit more difficult, whether ehm	Seen by as others as? Soft, female, Men don't talk about it Rationality, know the way	Head means you lead, with rationality? Are there answers?	Desire for leadership, certainty, holding

	(.). Do they think it's not macho or to discuss things? I don't don't know, they're suppose to be the head of the household and eh, know the answer? I don't know, don't know what it is. I know the boys have always been if there's any current or something, the boys were always more difficult then I mean my middle son anyway, you ring up Hi [NAME] how are you? Fine. Any news? No (laughs)		Lots of I don't know, irrational? Current problems can be dealt with by kids, but not ones in the future	
	<i>Section removed</i>			
CL	So what, what is holding you back from bring the topic, putting the topic on the table?			
Liz	I don't know the answer to that. I don't. I think probably I want it all in place. I'm going, here I say, I'm going to do it last week. I'm going to make an appointment with the GP and take this form and I want to discuss it with the GP. But I haven't quite got there yet and so I can't answer your question really because eh, is it embarrassment is it that I'm frightened of upsetting them cause I	Broaching subject: upset caused. Better not to see as dead anyway Looking towards GP to discuss it all Needs others to give answers. Need to protect others from death Internal and external barriers	Desire to control it all, know the answers, but has not got them. How does that feel? Uncertainty as not have the answers	Medics know and will give certainty.

	mentioned it already. I don't know, I can't answer that question.			
CL	Mmm			
Liz	Ehm, must be something holding me back. I don't know, no time perhaps, don't know who to go to first? Ehm, waiting for the right moment, I don't know. It must be one of those I suppose.	Right moment for talking and dying needed	Something controls, who or what holds back?	Societal control that we/ parents don't talk to children, do not upset them
CL	Yeah well, its not an easy not a easy thing. So the GP is on the list of people to talk to as well?			
Liz	Yes yeah, well only cause at the last U3A meeting one of the ladies said she'd done it said she found it very useful cause she was able to put it in the right terminology and he sort of advised, well not advised her really, but eh, yes advised her, on how to put how she felt really. She said it she found it was a big help to go and fill in the form so.	Others have completed living will and are encouraging Knowledge required, otherwise not legal	He helped her to put how she felt? Did she not know herself? Did he know her better? Thankful, subjected	Expert language Expert knowledge
CL	Hmm			
Liz	I asked [NAME] to make an appointment asking which one, cause she said to ask at the surgery which one would be			
CL	Hmm			

Liz	Ehm, in favour of it, cause they're not all and if you're going for help, you want somebody that is on your side, don't you really.	For or against, like members of the groups	They: not helping, need others It: can't name it	Doctors can make or break a living will: power. Can they be neutral?
CL	Hmm			
Liz	So, ehm, got to do that, but I am going any way next week, so eh, I'll talk to the desk then and see if I can make an appointment cause you've got to make you'd have to make an appointment eh you know wouldn't like to go, it's a ehm. It's not really a matter of great urgency and you know, I'd like to do it when it convenient for them really so.	Not urgent, not taking up space or death not life threatening Can euthanasia and ad be a convenient death?	Talk to the desk? Where are the people? Repeat: emphasis You have to wait in line, counted, to suit doctors Lots of ifs?	Do we behave to suit doctors? Is that our role as patients? Not seen as human?
	<i>Section removed</i>			
Liz	Njaa, I think probably a couple of the lady doctors. I want to go and see a lady doctor ehm, the one that is in [NAME], I've always found her sensible and very level headed and I find her easy to talk to, but I don't know whether she is in favour of this or not, cause I haven't asked.	Female can be both soft and hard Needs rational head	Gender issue? Boys need to be head, but female GP is level headed.	What is societies view of women and men?
CL	It's an interesting challenge, isn't it, like you say to find a doctor.			

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CL	It's an interesting challenge, isn't it, like you say to find a doctor.			
Liz	Yes yes yeah			
CL	Who will be sympathetic to			
Liz	Well this particular lady actually that I'm talking about, had the help from the GP, the GP was Indian which	Cultural assumption Modern thinking,	Not expecting positive response Or is modern	But might not be

	<p>was a big surprise and she said she was absolutely marvellous and that's, I wouldn't have thought they had eh she would have been sympathetic to it at all but. Sort of thing, you know, modern thinking you see, it's coming more and more and more to the for everywhere, I would think.</p>	<p>perhaps not open to older people</p> <p>Taking a stance</p>	<p>thinking not seen in doctors</p> <p>What is modern thinking? No escaping from</p>	<p>able to escape if there is more of it? More people talking about eu/as</p> <p>People power?</p>
CL	<p>When did you first begin to consider this?</p> <p>When did this first come to your mind?</p>			
Liz	<p>I suppose I have always said (..) ehm eh. I think probably first time [NAME] and I discussed it, was eh we bought a boat. And eh, (..) we, we keep it in [NAME], and he sort of we started talking then but he (laughs) always said 'if I die on the boat, just sling me over the side' (laugh)</p>	<p>Easiness of death</p>		
CL	<p>(laugh) yeah</p>			
Liz	<p>And it's a and eh, and so I suppose really it all started on from there and you sort of, cause that seed then is put in mind and we'd always said 'we'd have us cremated where ever we are' and bring the ashes home. (.) And then,</p>	<p>Grow into thinking about it, get accustomed to it.</p> <p>Death in old age is a expected and anticipated</p>	<p>Seeds can grow, need to start somewhere.</p> <p>Does it matter what happens after your death? Or only before?</p> <p>Good death is</p>	<p>There is a way of</p>

	<p>but then we discovered they don't cremate in [NAME] anyway, but anyway that is beside the point. And it sort of went on from there really and things come up and you start to talk about it and then (.) I think it was probably the Julie Walters film. I definitely think really, when I watched that I thought how wonderful, you know and how lovely. Cause finally she had the support of her family and she just went when it was time and that to me was lovely. Yes, so I suppose that was really when I made my mind up yes that was what I wanted to do, <i>I'd like to do that</i> but I don't know if I have the money to do it, just hope it's available here by the time I go, cause I'm not planning on going yet (laughs).</p>	<p>Impact of media, also Australian doctor</p> <p>Right time again?</p> <p>Self determination but with support from family. There is an ideal way of doing it.</p>	<p>with support of family/ and around you. But acknowledge struggle: finally!</p> <p>Words used not normally associated with death and dying</p> <p>Money= power, otherwise no control</p>	<p>dying well.</p>
	<p><i>Section removed</i></p>			
CL	<p>Thing, there was nothing in your personal life that sort of triggered off?</p>			
Liz	<p>(..)Yes, I suppose that again, eh (..) in a way, eh my father (..) ehm,</p>	<p>Father not involved in decision, so although she wants</p>	<p>Watching others suffer and die</p>	<p>Gaze</p>

<p>died very suddenly, ehm. Both my parents did, but eh in completely different circumstances really. And, eh, my father, I sat by father's bedside in the hospital and they came to turn him and eh, he died. And eh, (.) he wasn't for resuscitation. My brother and I discussed this and eh (..), we didn't actually discuss it with my father but eh I mean after my mother died, he didn't want to live anyway, in a dreadful state really. Eh, (.) and ehm when I saw him half an hour later, he looked so peaceful. ehm Cause he needed a heart valve, so he didn't have a very good quality of life the last few months really and he looked so much happier and so young. So much younger and yet my mother died unexpectedly and when I saw her, my mother wasn't there. What, what was that? She just wasn't there at all. It was just a shell and se. I can never quite explain that to myself really but I think it was</p>	<p>to decide herself, does not apply to others.</p> <p>Experience of making decisions for others, taking responsibility,</p> <p>Discussion earlier about needing others to make decisions for you</p> <p>Disintegration of body, is that the self? Not wanting to wait for death. Not physical suffering, but ageing process</p> <p>Dead before dead</p> <p>Putting self in others shoes</p> <p>Disintegrating, with horrible image</p> <p>Not letting others suffer through watching me suffer</p> <p>Mercy killing/ slippery slope?</p>	<p>Sense of knowing dad well and feeling able to make decision on his behalf.</p> <p>Again words un-associated with death and dying</p> <p>Watching again and being watched.</p> <p>Watching others</p> <p>No control, <i>sat in a nursing home</i></p>	<p>Knowledge of others better than of ourselves?</p> <p>Gaze</p> <p>As a society what do we consider a life worth living? Who sets standards?</p> <p>Why is society tolerating this? For somebody with capacity? There is a control mechanism, that stops action</p>
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	<p>when my dad, I'd said, in that moment she said he wasn't for resuscitation the nurse and I said 'that's right', and I thought 'oh my God, I'm signing my father's death warrant here'. But no, you know, that's fine. And when I saw him, I was so sure I'd done the right thing. Because he looked so lovely and I suppose that as well, <i>that made me decide</i>. And [NAME]'s mum, that was sat in a nursing home for 3 and a half years. Her mind was active and her body just decayed about her. And there was no way I'd want to go through that what she did or for her, my children neither. Cause eh, you know, every day you went, she wanted to die. I mean that's awful, isn't it, you know. I mean there are times really, if she had asked me I might have put a pillow over her head myself, really cause I just felt so sorry for her. But I didn't (laughs)</p>			
	<p><i>Section removed</i></p>			
<p>Liz</p>	<p>Yes, and seeing the alternative with</p>	<p>Length of time of suffering</p>	<p>Watching others is unbearable.</p>	<p>Things get decided for you,</p>

	<p>[NAME]'s mum really. Ehm, cause although my dad was ill for three, three months, he, I mean mentally as well he wasn't very well. So that was why he had to go, he couldn't, couldn't live at home cause he, <i>oh dear (laughs) terrible, oh dear, anyway. Ehm (..) so ehm (.),</i> but seeing [NAME]'s mum just decaying there. Oh God, couldn't stuff that, I think I'd might probably take the tablet myself if I was in that situation (laughs) I think so</p>	<p>He had to go, no choice, decided for him?</p>	<p>Quiet voice in reflection</p> <p>Call for God to intervene? Use his power?</p>	<p>subject status, but then you have to sit and wait for death without any body assisting? Not noticed?</p>
	<p><i>Section removed</i></p>			
Liz	<p>It was dreadful</p>	<p>Sense of anticipation</p>		
CL	<p>So seeing other people and growing older and facing deterioration, what would it be like if somebody said to you, one of your loved ones, I've made arrangements and this is what I like to see happen to me at the end of my life? How would that be?</p>			
Liz	<p>I would be quite pleased about that. Ehm, I don't think, ehm (.) I don't think it would be a problem. I don't know cause I haven't experienced it</p>	<p>How can we decide, not knowing the place?</p>	<p>Can give approval to others.</p> <p>Others do not see what you see, feel</p>	

<p>but I don't think it would be a problem. I mean I just had, ehm don't know whether you could call it similar even really, but a friend of mine who's just had to have her dog put down, eh now this friend is like a sister, we do a lot together, and you know, I'm, I'm a big animal lover. And belief you me, you know, I have mourned when I have lost dogs in the past but eh. But just recently her dog has been ill and I, you know, I just kept saying to [NAME] 'its time, why don't you take her to the vets', you know, 'he is suffering'. 'Oh, he can't be suffering. He brought the stick to me today'. I said 'once [NAME], once', you know, 'you're having to feed him'. And I was almost pleading with her really to go and have him put down and (laughs). It's terrible really, you don't tell but you do I suppose really (laughs). But no, I honestly hate to see anybody suffering. Eh, I mean I've seen it in my job, you know. I</p>	<p>Sense that animals cause similar grief than people</p> <p>How do people see the need in others? Do their own needs get in the way?</p> <p>Desperate</p>	<p>what you feel.</p> <p>Detached from an animal and non family</p> <p>Do not tell what?</p>	
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	suppose it's not the same as family, but I don't think I would have a problem with it.			
CL	Mmm			
Liz	I don't think. You can't say definitely until you have experienced it, but I don't think so, I would think it would be sensible		Need to be rational/ sensible. Can you be sensible and rational about such an emotive topic	
CL	Even if it was the kids, the children would come with that suggestion? Now I know you've said before the kids			
Liz	Well I'm sure they wouldn't, but if they did, yes I can appreciate that, yes. I mean because (.) more than likely I won't be here then anyway I hope not but	Expecting the normal sequence of dying, the acceptable order	Do you know them (better) Referring to own death, as to not having to face the unthinkable	
CL	Mmm			
Liz	And I've said that is a terrible thing when a mother has to bury her children but		(Un) Deserved death	
CL	Mmm			
Liz	So hope it doesn't happen but eh I (..) yeah (..) mm (.) Yes, cause if one of them was ill and eh, yes I I would want them to, yeah. I think actually in a lot of ways it makes it easier for everybody, if you know, eh, and if the	Can not consider this option No corruption, bad feelings Prognosis is poor Not done anything wrong	Easier for others, what about the person, does this feed into abuse discourse? The hospital comes: anonymous other	Medics know when there is no more to do and we accept that

	hospital come to you, and say ‘I’m sorry but there is nothing we can do for Mary’, or what ever her name is, you know. You can say with a clear conscious ‘yes, ok then, that is fine, that is what she would have wanted’. (..) So yeah, I don’t think I would have a problem with that, yeah		Still confused about what eu/as is!	
CL	So, in the living will obviously you can’t specify as we said, that you want euthanasia or assisted suicide, cause it is not legal in this country			
Liz	Yeah			
CL	Eh, how far would you go to perhaps have your wishes			
	To fin? My own life? (...) oh. (.) That again really would depend on how much I was able to do anything wouldn’t really. But I would hope eh (.), you can only write it down really, (..) cause I believe when you go into hospital, they have to give you food and water, don’t they? And what have you, eh, (.) so I don’t know really what else you could do, if eh you write your wishes down and hope that.	Lack of clarity as to what can be done Obliged to look after you, but only the minimum, like a plant All you can do is hope, no real influence	Sense of being lost in it all In the hands of the doctors Can not escape from hospital? Why not? Can you refuse treatment? Seems unthinkable	Object in hospital they have to look after you. Complying with the position of patient, could not sign out? Powerless

	But what, you know, cause presumably I be ill. I couldn't sign myself out of a hospital or do anything like that. You just have to hope that they would be sympathetic to your request really, ehm (..)			
CL	Of course it couldn't be euthanasia or assisted suicide, cause that wouldn't be legalised in this country.			
Liz	Ehm (...) yeah, eh (...) I don't know. What could you do then, what could you do?	No solution available, thinking restricted by current discourses?		Powerless
	<i>Section removed</i>			
Liz	You, you're, I mean now, I could, I mean, I don't know. Don't know what I'd do really cause again I don't, I don't think you can answer a lot of these questions really until you're actually faced with it. Because eh you don't know how you're going to react. I had something completely different happening the other day and somebody said 'oh, I wouldn't do that and do that'. I said 'but would you? You know really, if it came to it, would you?'	Garbled language Uncertainty about wishes, circumstances can change	Lot about knowing and not knowing. Interlinking of rationality and emotional, change How can be so definite before and doubtful now?	What counts? Rationality or emotional response

	Ehm, (..) you don't know, you'd like to think 'oh yes, you know, I'd do this, this and this but eh (.) I don't know, don't know what you could do, so all you			
CL	Mmm			
Liz	Can do really is write. I mean if euthanasia and all these things are legal in this country, then well, I suppose, then it would be easier, wouldn't it? But if it isn't (.) eehmm (.) and if I didn't have the money to go abroad (.) ehm (.), I'd just have to hope that my wishes were (..) I don't know.	Legalising would solve problem? Money= power Doubt	Euthanasia and all these things? What else can there be?	No impact
CL	Mmm, so (.) in terms of the legal position in this country, would you like to see the law changed?			
Liz	Definitely	Certainty again		
CL	Would you?			
Liz	Yes definitely, yes		Strength of statement, in light of previous doubt	
CL	To stipulate what? What would it need to say?			
Liz	(.) Wah, I'd like a similar set up that there is in Holland eh, that that you could really, and you could bank on, you know, your wishes being ehm (.) carried out. (.)	Reliable Certainty about the end being the end?	even in current banking crisis? Living? Is it living? What are you not	No sense of control/ power over having wishes carried out: others decide. Is making your own decisions

	Ehm, that when (.), you know, the end it was the end and you didn't have to linger on (.) and or live with under great difficulty. Suppose it's a coward's way out really, isn't it, when you think about it. In some ways (laughs)		facing up? Who calls you a coward?	being a coward? As power taken away from those that normally exert it?
CL	Say a bit more about that, a coward's way.			
Liz	A coward, well that you you know you, I suppose (..) unless I can live like this, I don't want to live where I'm dependent on other people and eh you know in any pain not strong enough oh well, I don't know. But I always seems to me really as if it is a little bit of a coward's way out but then on the other hand it takes courage to do it so eh mmm	Dependency Courage vs coward	What is considered normal/ acceptable? Who labels? Who/ what do we conform to.	Is this a normalising judgement?
CL	(..) Mmm			
Liz	So			
CL	Talking about it when you say you can't really tell unless it sort of faces you, what you might do. Have you got a sense you might change your mind? As things change in your life?			
Liz	I don't think so, no I don't think I'd change my mind. No, no I	Certainty with some ambivalence		Not even wanting control: ambivalence

	<p>don't think I'd change my mind (...). Ehm, I suppose I just hope that it it never comes and that I just have a heart attack or I'm run over by a bus or something (laughs). That's how we all want to go, isn't?</p>	<p>Not wanting to face it really. Wanting quick death</p>	<p>Does not want to make decision, take out of every bodies hands</p>	
CL	<p>Yeah</p>			
Liz	<p>And that we don't have to make that decision and eh just hope. I mean that's a, that is a cowardis way, isn't it. I want to just go, I don't want any of the suffering or anything (.) ehm. But no, I don't think I'd change my mind. No, I'm quite my mind up, I'm quite happy with that in my mind and if I'm happy, that's it, you know and I will stick to it.</p>	<p>Rigidity</p>	<p>Not even sure what she has made her mind up about</p> <p>Rigid like people who do not want to talk about it</p>	
CL	<p>And it sounds as well it has been there for quite some time now</p>			
Liz	<p>Yes, yes I mean we have been going to these meetings for over a year really, so it's taken it nice and slowly and be able to think it all through. I mean I suppose I'm not clear on a lot of things, ehm but you know I know what I want to do at the end (.) eh</p>	<p>Well considered</p> <p>But acknowledges limitations</p>	<p>Not impulsive, rational</p>	

CL	<p>What made you decide to go to the meetings? Cause I'm presuming they would have been advertised and what made you think oeh that sounds</p>			
Liz	<p>Well I suppose I thought I I would learn about it. Yes I like I like knowing. I mean I'm not very clever, intelligent person, but I like I I I like to know about things. I'm interested and I went along really not really knowing how I'd felt at the time, but I listened, and eh listened to people and people say give their thoughts and you think 'yes', (.) ehm (.) you know and eh (.) And again I think [NAME]'s mum, that really, really, you know, sickened us both to think that there wasn't something that we could have done for her. I think eh (...) and also with my dad really you know how lovely he looked. I can see him now, you know, how relaxed and happy he looked after the trauma he'd lived through for the last, you know, three, six months before</p>	<p>Need for intellect to think this through</p> <p>Being open to ideas, freely given ideas</p> <p>Guilt?</p> <p>Experience that death can be a blessing, release</p>	<p>what about people who are not so clever?</p> <p>Watching mother in law, again physical response to seeing suffering</p> <p>Powerless in both cases, in one death came quicker</p>	<p>Knowledge is required</p> <p>Death as a good thing</p>

	that. (..) (Laughs)			
CL	Mmm			
Liz	<p>I mean, he used to go to ASDA and leave his car and forget where he'd put it. I used to take him a hot meal every day and put it in the fridge and you'd ring up at teatime, I went every day, ring up at teatime and 'You'd had your dinner dad?' 'Yeh'. 'What're you doing dad?' 'No, I'm just having a brandy'. 'Ok. Eh, (.) What did you have for your tea?' 'Filet steak'. Every day it was filet steak and I'd go home the next day and the dinner would still be there. (laughs) I mean it's funny now, but it wasn't at the time. Yeah. (..) But, I'd said to you early that dementia wouldn't be a problem cause he was as happy as a pig in muck. It was everybody else that had the worry. So, ehm, you know if I was demented, which I'm quite sure I am sometimes (laughs), when you walk into a room and you can't remember what you've come for ehm, (..) you know I</p>	<p>Loose the plot of the journey and vehicle</p> <p>Animal analogy: feeding</p> <p>What looks difficult for others, might be alright for the person</p>	<p>Desire to feed others, but they do not feed themselves</p> <p>You need awareness of your destiny</p> <p>Lost his mind, not rational, can not assess his situation, as earlier on talked about trauma</p> <p>Not rational</p>	

	wouldn't be aware of that I don't think.			
CL	So that wouldn't be part of your not a reasonable life. Dementia would be ok, that wouldn't be part of that equation?			
Liz	(..) Well, (..) I suppose it would when I got to the end. But eh, cause actually when, funnily enough, we went somewhere on Tuesday night up to Liverpool and this lady came in with this chap, ogh dear me, and he was obviously suffering from some form of dementia cause they brought him and it tickled me really. There was this lady, a gentleman and presumably her husband and they sat this pint of beer in front of him and he just sat there like this all night. 'T was a jazz concert and he just sat there and I kept looking across you know and I thought 'I wonder if he knows he's got to drink that drink out of his glass' cause I didn't see anybody feed him with it. They just plonked it in front of him and you know he wasn't even really	<p>Sense of inactivity and not being looked after, attended to.</p> <p>Commenting on care provided by others which does not sound dignified</p> <p>I am full of life in contrast to the other person</p>	<p>How does society deal with people who we don't want to become</p> <p>Can label people, signs of illness obvious</p> <p>Can't look away, need to watch, monitor?</p>	<p>There, but not noticed, not checked on, no surveillance</p> <p>Categorize people via label</p>

	looking at it. I wouldn't like to be like that. No, but I'm sure he wasn't aware of it, you see, was he? And se, you know they'd take his coat off or I say?? Oh dear, anyway that's nothing to do with this really			
	<i>Section removed</i>			
Liz	No, I was. The only things I'd probably would want to ask eh eh (.) and really its not your department really was eh (..) ehm (.) if you'd thought we should get this sanctioned with a solicitor or something like that. Some do and some don't. I couldn't see the point really but ehm (.)	Who can approve it, not wanting to spend the money If it is legal, it will be taken serious	I want somebody to endorse my views	Lawyers hold power
CL	The living wills you mean (.) ehm			
Liz	Would it be better if it was endorsed? But I mean, it's not really your department, is it? You know.		Somebody needs to say you have done the right thing	Judged by others, checked out
	<i>Section removed</i>			
Liz	That is why ehm (.) because ehm (.) as this lady said they would tell you. You know, without influencing you, but tell you how to how to write it down and how to answer the questions. So everything.	Influencing/power	Will tell, how can they not influence	Somebody else knows, will instruct you and you follow instructions
	<i>Section removed</i>			

Liz	<p>Yes, quite right. Because, I mean, not on this subject, but our neighbour has just moved house and eh went to his surgery to tell them in the surgery and they said he had to go to the hospital and change his address at the hospital. You know, wouldn't you have thought that they could have done that at the surgery with the medical records? I mean what's all these millions of pounds we've paid for these computers for? You can't change your address (laughs). Oh dear, and I mean, not that obviously then you see, leads you on if you do lodge a case with your doctor, you know, who is to say? You probably got more likelihood of somebody down in Cornwall or somewhere picking it up, cause they would have to look on your record, wouldn't they? But eh (.)</p>	<p>Not trusting health service, seen as incompetent to make decisions. Who are they to decide for us</p>	<p>All very removed and mechanical, no longer knowing the person</p> <p>Said with energy/anger If doctors are so clever, why can't they sort this out?</p>	<p>We are monitored, but if we do not tell them, they will not find us. Can we escape the surveillance?</p>
	<p><i>Section removed</i></p>			
Liz	<p>Yes, yes, we were discussing that really whether, you know, Dignitas could provide, you know,</p>	<p>Marked as belonging</p>	<p>What is their group: old and about to die?</p>	<p>Group identity, behave accordingly</p>

	like the diabetic people do			
CL	Right			
Liz	I mean, I'm on Warfarin, I have to carry a Warfarin card round with me. Ehm, so ehm (.) But you know, if they had a bracelet or something like that, that you wore all the time, that would be	If we can't talk about it, have other signs	Challenging existing thinking	
CL	It would alert people			
Liz	That would work really. But I think we got to go a bit further down the road before we get that. (laughs)		Others not ready for it You/ society needs to be ready for it	How do you bring about change?
CL	Yeah, yeah			
Liz	It would have to be, I mean I think we're getting there but it is we would have to be more recognised, I think	Who would know (think of Beth, badge)	Known as a separate group with identity	Behave according to group identity
CL	Mmm			
Liz	Cause otherwise people wouldn't know what the hell you were wearing it for anyway so (laughs)	Us and them	Related to the devil	
	<i>Section removed</i>			
Liz	No, it's been I really enjoyed it actually. You're very good cause you have made me think ehm (.) that there is still a lot of questions really that I need to answer that		Think: use rational side, not only emotional	Do rational arguments hold up better than emotive ones?
CL	Mmm			
Liz	That I hadn't really, you know, thought	Like her friend said at the beginning		

	about I have to say, but it I won't change my mind			
	<i>Section removed</i>			

Appendix 2.4 Examples of Discourses

Below are further sections of other interviews not referred to in the text, illustrating the presented main discourses. Longer extracts are presented to give a flavour of the conversations. Some sections can illustrate several different discourses, but are quoted under the most prominent discourse. Texts are not repeated here, if they have been presented in the text.

Examples of the Foucauldian concepts are indicated in the third column.

K=Knowledge

P=Power

Sub=Subjectification

Sur= Surveillance

Bold: said with emphasis, louder voice

Italic: said softer, quieter, under breath

Underscore: author's emphasis

(.) noticeable breathing space, (..) 3-5 seconds pause, (...) more than 5 second pause

[] replacements to maintain confidentiality, clarify meaning and enhance readability

Confused discourses

Beth	Euthanasia can be carried out without a person's consent (..) I could, I could ask someone to put me to sleep euth, with euthanasia because that would benefit me . I think I'd need somebody to help me do it, <u>which I think is</u> , is euthanasia.	K: incorrect K: doubt of self
Ellen	But if it came to the time, when, as I say, I was, I was desperately ill and the doctor said 'you're dying and you're not going to be in agony for, for the rest of your life', that to me is <u>euthanasia, assisted, assisted, not suicide, assisted death, I think.</u>	P: Doctor said K: doubt
Andy	Yeah, it's, it's a, there's a diff, I'm not very clever with words really. But there is eh a division, isn't there, between euthanasia and, and, and, and suicide, is it? Ehm, subtle difference. Eh, Euthanasia, well euthanasia is where, if, <u>if I remember rightly</u> , ehm you're assisted to die, <u>is that right?</u> I don't have clear in my own mind, quite apart from your question, the exact meanings of these words. That's why I am sort of hesitating. Ehm (..)	K: not expert, doubt

Liz	<p>Euthanasia is a way of ending life, ehm, without pain, and just sleeping away, <u>isn't it?</u></p> <p>How are [eu/as] different? (..) Thsj I don't really know really actually, now you think you know, now you say really ehm cause the end is the same but eh (...) eh (.) I don't know.</p> <p>This is the one reason why I think it is so difficult to get it through [legally] because <u>you're asking somebody else then to take responsibility,</u></p> <p>(.) It's funny this really this, isn't? Cause I've always been quite definite about what I want, but you you're putting questions in my mind now you see.</p> <p>I'd be quite happy to take a tablet, I'm quite happy to have an injection and to just go. So I suppose really that is assisted suicide then, <u>isn't it really?</u> It's <u>not euthanasia, is it?</u> Is it if you have an injection and you go <u>is that the same</u> as a tablet or?</p>	<p>K: limited</p> <p>K: incorrect</p> <p>K: doubt, self doubt</p> <p>P: take, have (passive)</p> <p>K: doubt</p>
Iris	<p>CL: what you think euthanasia means? (.) Helping somebody to end their life. CL: what would you say assisted suicide means? (.) Yes, because I would have said that is probably the same, so which obviously there is a difference. (...) (sigh) (...) (...) But is quite difficult to know the difference between the two.</p> <p>Euthanasia, I suspect, would be more (cough) could come to the stage of <u>somebody else deciding for that person and deciding that (.) they don't need to live any longer, rather than it being the individual's decision. (..)</u></p>	<p>K: lack of</p> <p>K: incorrect</p> <p>P: somebody else decides</p>
Violet	<p>Assisted suicide I think is just one step back from that where somebody again has <u>chosen to die in their own time.</u> That's what I think, that it's <u>somebody whose clear who that they want to die and they're clear</u> that they would want some sort of support and help.</p>	<p>K: self</p>

Self-determination discourse

Beth	I think there, some people who want to die, they're quite justified in wanting to die and after all, it is them that are doing the suffering.	K: about self P: internal, given to person
Ellen	<p>I can, can say when I want my life to end.</p> <p>It's about <u>what you want</u>, not what anybody else wants, it's about <u>what you want</u>.</p> <p>That's my body saying, that's me saying, it's my body <u>I'll do what I want to do with this</u>.</p> <p>I think really everybody should be <u>given the chance</u> to say yes or no, whether they want to or not. And there'll be hundred and thousands of people will say 'oh no, where there is life, there is death. As my friend did. Ehm (.) but no not to me. (.) I just think <u>you should go when you want to go</u>.</p>	<p>P: internal assuming no other influences</p> <p>P, Sub: body seen as separate K: self</p> <p>P: controlled by others</p>
Andy	<p>It should be with your own previous <u>connivance</u>.</p> <p>I've got my own ideas, where I, when it is my time, <u>I wanna go and that's it</u>. I've no doubt in my mind.</p> <p>We call ourselves a free society, <u>so we should be able to do what we want to do</u>. <u>We're not of course</u>.</p> <p>If that's what you want when your allotted span comes, comes to its end, which is its time, eh that's what you wanna do, fine. It's your life, it's your decision. You should be able to make that decision'.</p> <p>It's a choice, it's nobody saying because you can't wash your teeth, can't wash your socks and clean you teeth, you've gotto go. No question of that. <u>It's a choice thing</u>.</p>	<p>P</p> <p>P: other factors</p> <p>Sub/ Sur: others views and observations</p>
Liz	There are times I wake up and I feel like death. You know, I feel ninety, never mind 68, and if you were suffering from depression or something, I mean it wouldn't make any difference to you cause you'd be gone and you wouldn't	P: who controls?

	<p>know, but whether you might be tempted to take [the pill] before. I, it worries me, worries me, <i>that</i>. Just in case at some point then there is <u>a risk that one day I wake up and I feel a bit pff depressed and miserable and I'll take it.</u></p> <p>I would say you know I would be quite happy to say '<u>yes, this is the time, I want to go</u>' and then eh, I mean, <u>they can put gas on me or do what they want.</u></p>	<p>P: who controls, self (I) or others (they)?</p>
Iris	<p>People with slow progressive degenerative diseases very often are the ones who are fighting for eh end to end their lives. Because they actually want to end their life before they get, they know what the prognosis is going to be and they know what the stages of the illness are probably going to be, <u>so they actually want to end their life before they get to that stage.</u> So, that I think is slightly different from (.) somebody who is (.) terminally ill and maybe (..) wants a bit more compassion as in 'why would I go through another two or three weeks of pain', because that is all it is going to be.</p> <p>The aspect of changing the law would have to be very much on the respect of (.) giving patients that that empowerment, <u>not giving doctors or anybody else around that empowerment to do it.</u></p>	<p>K: medical prognosis, trusted as true</p> <p>P: role of doctors</p>
Violet	<p>The death wish person, <u>who is clear about their own choices</u> ehm needs help.</p> <p>The central person in this has made a clear choice to have their life end at the moment of their choosing <u>not at the moment of just ordinary life span or a medical person or a religious person.</u> Ehm they want to <u>be in control</u> of presumably being in control <u>all their lives about their choices</u> and they want also to have the respect of being able to be in control of their life end but they need either help support or help in <u>breaking through the system which doesn't want to give them support.</u></p> <p>There is a great deal of shock and horror about somebody saying clearly 'I choose to die at the moment of my choosing'. That there is ehm all all <u>the big systems</u> are between the person and the death of their choice, ehm, the <u>hospitals, the medical profession, the church, the state ehm.</u></p>	<p>Sub: no name for this position</p> <p>P: self vs others</p> <p>Who is stronger?</p> <p>P: institutions, nameless</p>

	<p>I have (.) been given the <u>privilege and the obligation</u> to make many choices in my own life, and I feel that <u>this is a final choice</u>.</p> <p>I can't see how anybody can say to a non-believing person, this is the <u>rule of the church</u>. It doesn't, it doesn't obtain for them except so far insofar that we're a Christian country, so called.</p>	<p>P: anonymous anybody, Sub: Christian</p>
Ester	<p>Euthanasia for me would be the ability to end my life <u>when I want to</u></p> <p>All I want is to be able to end my life.</p>	<p>P</p>

Medicalisation of dying

Beth	<p>There are figures given for <u>doctors who help people on their way to die now</u>. They're not supposed to, but there's a very peculiar grey area, because if they're giving giving drugs, certain drugs, to alleviate pain, and keep the patient comfortable. <u>If they choose to give a little bit more</u> of that drug, that could hasten that patient's death. And who's to say exactly where the borderline is. It's a grey area.</p> <p>People wouldn't let you do it as it were, <u>they'd want to save you</u>. People would always want to save you cause they think that is the right thing. CL: Whose people? Who'd want to save you? (..) Well, I think everybody. I think family, friends, all the public services. (..) Cause that is the mind set, isn't? CL: Tell me a bit more about this mind set? Well, I think most people think it is always right to safe life, you should always save lives if you possibly can.</p>	<p>P: use medical K, they choose No Sur for them</p> <p>P: anonymous others Sub: accept 'others' views</p>
Ellen	<p>If the doctor said to me I have six months to live, but you are gonna be in absolute agony, well I didn't, wouldn't want that.</p> <p>The doctor has got to say 'Yes I agree' or 'you're, you're of sound mind to do it'</p>	<p>K: medical Sub: patient rejects</p> <p>K: mental health P K</p>

	<p>And I'd rather <u>somebody said to me</u> 'right you can, you, you can't' you're not, you're not gonna get any better, and <u>I think now is the time for you to go.</u>' And I would say 'yeh'</p> <p>I said '[my mother] won't be in any <u>pain</u>?' And he said 'Oh no, we make sure she isn't' and I then think to myself '<u>do they help, do they assist in some way?</u>'. And I hope they do (.).</p> <p>I hope they do, and I just hope that they, <u>they use their own</u> (.), <u>don't know, intelligence</u>, to say that she, they're not going to get better, just give them a little bit more morphine, or whatever it is, and that to me should happen. <i>But, I don't know, I don't know.</i></p> <p>The doctor said 'I'm 99% sure you haven't got anything wrong', but I knew there was.</p>	<p>K P: others judge Subj: agree</p> <p>K P No Sur of them</p> <p>K: rated higher</p> <p>K: incorrect</p>
Andy	<p>The <u>medics</u> have, we've gotta <u>keep this people, this person, alive</u>, you know. Hey, they, <u>they're in a conflict</u>, I can see you know, they've a professional, Hippocratic Oath and <u>their whole life has been spend training for and keeping people alive.</u></p>	<p>P: by others on medics</p>
Iris	<p>This is going to be the next stage [in a progressive condition] and actually I don't want to go that way. Where in certain terminal illnesses, you don't necessarily have that same, <u>same knowledge?</u></p> <p>I think it's very difficult for people and some of the work I have been doing part with consultants and GP's, very difficult to necessarily suddenly say 'well, this is the point'.</p> <p>I don't see why people should have to suffer excruciating pain, just because it's, you know, <u>the book says</u> oh well at the moment we just give this now.</p> <p>There's some quite <u>clear assessment</u> of where that person was, so you know so they would need support and assessment and what ever you'd want at that stage for doing it but, so that</p>	<p>K: questioned</p> <p>K: questioned</p> <p>K P: not follow book Sub: why have pain</p> <p>K: rated higher P</p>

	<p><u>somebody in a skilled position</u> would be able to understand them and work with that person <u>to see if it was actually right</u>,</p>	Sub: person does not know self, gets checked
Violet	<p>And seeing that somebody could actually say '<u>I choose not to be treated</u>'.</p> <p>Time was when it was in the family, it happened together in the family. This business of being <u>rushed to hospital, when you're about to die</u>, seems such a cruel thing.</p>	Not Sub P Sub
Ester	<p>Mum wasn't diagnosed by the GP for three months, he still practise but shouldn't be, he is renowned as incompetent.</p> <p>And to <u>put a, a feeding tube</u> the ni, when [a friend] was at that stage and it was <u>obvious she was going</u>. That, I don't want either.</p> <p>And <u>doctors are not perfect</u>, the nursing is often left to <u>nurses</u> as well and they're <u>not perfect</u>. It there is a risk of not being looked after properly, whether it is with a doctor, a nurse or the family and that risk I don't want to take.</p>	K: questioned K: questioned P Sub K: questioned

Becoming dependent

Beth	(..) I don't want to have <u>to rely</u> on family and friends.	P Sub
Ellen	<u>You don't want to be burden</u> , a burden, and I never, ever go to, I never worry about other people, <u>I never worry other people with my problems</u> . Cos I've got to get on with them.	P
Andy	<p>When my time comes and I'm no longer capable of washing my socks and cleaning my teeth, I don't wanna be around.</p> <p>I don't wanna be in that state and I've which is perhaps my consideration but <u>I don't want to be putting people into a situation where they'll have to look after me</u> in that state.</p> <p>You know what I mean, its not (.) but eh. I mean b be, lying</p>	P Sub Sur P: loss of

	<p>around for months or years in a, in a vegetative state or a stroke or eh something similar to that. I, I, I just don't want to do that. I want to be and indeed must put myself into a situation, where I can dispose of myself when the time comes.</p> <p>Absolutely, independence that's what's all about.</p>	<p>control Sub: put myself</p> <p>P</p>
Liz	<p>Unless I can live like this, I don't want to live where <u>I'm dependent on other people</u></p> <p>Again a really tricky questions. What does independence mean? C.L.: What? Can you define it? Be able <u>to look after myself</u> and not eh have <u>to rely on other people for ehm, normal functions</u> and eh, to be able to prepare food however simple just to be able to look after myself really.</p>	<p>P Sub Sur</p> <p>Sub Sur</p>
Iris	<p>I think it is difficult enough for relatives at the moment to have that <u>burden of caring</u> for somebody and that person desperately wanting to die. But if they actually help them at all, then they're gonna be taken to court, so they just got a double burden of grief really.</p>	
Ester	<p>I wouldn't want <u>to put them through</u> it either, if I had a child.</p> <p>I don't want to have to <u>be a nuisance to other people</u>, I haven't got really close family, I've got family, but they've got their lives and their own children to look after, who are all at the exciting stage of life.</p>	<p>P Not Sur</p>

An aged death

Beth	<p>I'm deteriorating physically (..) and you, it starts to make you think about what is the end going to be like (...).</p> <p>Well, because you don't know what you're going to have to face in the future and what ever it is, it's not gonna be pleasant. (..)</p> <p>I had this <u>stroke</u>, which made me think even more, you know, I'm <u>deteriorating physically</u> (..)and you, it starts to <u>make you think</u> about what is the end going to be like(...).</p>	
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	<p>When you <u>get to my age</u>, you know (..) well you sort of expect deterioration.</p> <p><u>I've had my life</u>, I've made my choices, and I've got off pretty lightly really from troubles.</p>	P
Ellen	<p>And it is strange cause my grandmother died when she was 74, my mother died when she was 74, so when 74 comes I will be quite {shah} saying 'oh jah, <u>its my turn</u>'. (..)That's</p>	Sub: personal
Andy	<p>Life rolls, or death rolls nearer (laughs).</p> <p>I mean If I'm fit and healthy and able to do things, fine, no problem. It's the being incapacitated or <u>totally incapacitated</u>, that, that really <u>worries me</u>.</p> <p>[Mother] just, you know, her <u>brain was still working</u> but her <u>body wouldn't work</u> and, and she couldn't clean her teeth.</p> <p>Oh ok, [My aunt] wasn't well and you could say in <u>the natural allotted span of these things, the time had come</u>.</p> <p>I'm finding now, I'm having to think about it, because <u>I'm finding I'm running out of steam</u>. And I don't want to get to the stage where I've only have enough steam left to breath. <u>There is no fun in that, just being sitting there, not capable of doing anything</u>. You see them in a nursing home, don't you, just sitting there, nothing happening at all. The brains might be there but there is nothing happening.</p> <p>Like I say, to be like my mother was, to be mentally sound but not to be able to look after myself and to have other, have other people running round after me, I would be getting pretty near the limit then.</p>	<p>S ub: incapacitated pers</p> <p>Sub: need working body</p> <p>Sub: old person</p> <p>Sub: nursing home resident P: passive</p> <p>P Sub</p>
Liz	<p><u>I don't want to linggger</u>, I don't want to linggger, ehm you know drifting in and out of consciousness and every body stood around your bed and oeff. No, or or (.), you know, be sat in a chair and not be able to (.) <u>function</u>, no.</p> <p>But I wouldn't like just to be stuck in a wheelchair in a house on my own and not be able to do anything. That would be,</p>	Sub

	<p>you know, <u>that's time to go</u>. As <u>you get older</u>..... You, you, you, your <u>horizons shorten and your expectancy shortens</u>.</p>	
Iris	<p>I think it's different because you don't, ehm. I suppose you even like <u>elderly people</u> generally, there seems to be a difference between that and having a <u>progressive defined illness</u>.</p>	<p>Sub: elderly people vs. progressive defined illness</p>
Violet	<p>So I'd say it's very <u>definitely a journey towards old age</u>. And being more aware that that it's coming sooner rather than later eh (..) but to be <u>absorbed and to be welcomed</u> into into into my life and into my thinking.</p>	
Ester	<p>To be in bed, to be topped and tailed by strangers, could be fed towards the end as [mother] got weaker and weaker and her brain was good. And towards the end she just spat it out 'I've had enough of all this'. And eh watching that, was horrendous and it wasn't fun for her and it certainly wasn't for me either. And I don't want that.</p> <p>They probably <u>won't have homes for us</u> anyway in twenties years' time (laughs), To feed and shove food in us or tubes.</p> <p>How many people have attentive families, who live around the corner, can give up their time <u>to see you through those last years</u>.</p> <p>Even with family around, I wouldn't like to be like mother. Being in a bed, being fed by the mouth for months on end, <u>knowing whether it is going to happen</u> in a certain time anyway.</p> <p>When you are in pain or can't cope with yourself or any of those <u>ageing factors</u>. Ageing has a lot of different aspects of it: but physical, mental, health (coughs) all those aspects are the main things. And <u>when it's getting too hard to cope on my own, I want to die</u>.</p> <p>What does matter is my being <u>able to do my own thing</u> in the house. If I can cook and do those things and I can get out. And life, particular when you're on your own, as a lot of us are, the things that are or make <u>life worthwhile</u> (coughs) are the things that you enjoy most. If I can't do that and <u>if I'm in</u></p>	<p>P Sub: be cared for Sur: watched</p> <p>P: shove Sub: resident</p> <p>P Sub</p> <p>Sub: absence</p> <p>Sub: what is a valued life?</p>

	<p><u>pain or if I'm totally incapable</u>, you know, why live? Why, there is no point.</p> <p>People are being encouraged or pushed into choosing euthanasia and assisted suicide. I can't see that that can be <u>any worse than go thru the hell of being maltreated in hospital or a nursing home</u>.</p> <p><u>You've just got to come to terms with it</u>, grow up, get a brain, think. Because it's part of life. It's sad, but it is part of life. Got to accept that, like all things, <u>it's part of life</u>.</p> <p>The best of it all, <u>goes to the young not to the old</u>.</p>	<p>P Sub</p> <p>Sub: not valued</p>
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An 'unbelievable' death, growth and nurture

Beth		
Ellen	<p>As [a friend] was reading this passage [from the bible], [mother] died. (.) She said it was a wonderful experience for her to, to be there, for my mother to die. It helped her die with dignity. I'm glad that [a friend] was with my mother because otherwise she wouldn't have had, she wouldn't have, anyone would have been there. But she did die, she said it was very, very peaceful and she said 'I thought it was lo, wonderful'. So I suppose in one way yes (.), my mother did die, how, how she wants to die, reading the scriptures from the bible.</p>	
Andy		
Liz		
Iris	<p>You can heal people into life or you can heal them into death. You make to make their, their <u>passing peaceful</u>.</p> <p>Ehm but so often in old age and in cancer care, as long as there is hope, as long as the spirit is going, then you can nurture people along. But when you get to a point where, actually the spirit is going and the person, no matter what, you can't actually lift them back up again, then I think you have to <u>show compassion and let them go</u>.</p> <p>So, having a good death is helping people to let go and be at peace and be where they want.</p>	<p>K P Sub: dying person</p> <p>Not Sub</p>

	<p>Healing isn't necessarily about a cure, is it? Healing is about helping that person to <u>be at peace with themselves</u> in what ever way. But there is a point where people are weary, what ever it is that they're, they're going through and so at that stage it is more about <u>helping them to die a good death</u>. Where they want to die, how they want to die, eh if possible and just making the environment and everything ok for them.</p>	<p>P</p>
<p>Violet</p>	<p>The interconnectedness of everything, ehm, and that the things in the winter, and the soil and the compost are part of a growing cycle and <u>to be born and to die</u> is just part of what you do, it's no big fear or drama. I hope, it's just the <u>next good thing</u>.</p> <p>People who sign their (.) choices, don't even activate them. But, <u>live more peacefully</u> because they know they're there.</p> <p>I would say 'no treatment thank you', I don't want to be vomiting and ill for six months, I'd rather have six or three months total (..), partly total anyway, <u>peace and quiet and enjoyment, and be tidied away and rounded off</u>. I see nothing wrong with that.</p> <p><u>My life is good</u>, my life has been good, and if it's not going to be great, now is the time. The <u>body has worn out</u>, what's wrong with that, I'm quite happy with that as a concept. It, it, It's having a good, a good death.</p> <p>I think that would be wonderful in fact, <u>choose the friends to support me and have a good time</u> and leave some good memories. Doesn't seem a bad thing. Ehm, (...) yeah cause my life is good, I don't really want it to go out on a <u>little bit of a whimper</u> (laughs)</p> <p>I suppose this it to do with the culture that we're so separated from death and so separated from it being a reality of life CL : Mmm Time was when it was in the family, it happened together in the family. This business of being rushed to hospital, when you're about to die, seems such a cruel thing.</p>	<p>P</p> <p>Not Sub</p> <p>P Sub Sur</p>
<p>Ester</p>	<p>[Father] was very lucky. He died in his bed <u>with</u> mother <u>caring</u> for him.</p>	<p>Not Sub Not Sur</p>

Silenced and being silenced

Beth	<p>I have no idea whether they've joined Dignity in Dying. And I mean I won't ask them.</p> <p>C.L. Have you discussed it with [your sons]? (Sigh). Well, they know I've got a living will and they know that I support Dignity and Dying. Ehm (.). But ehm (.) tj, we <u>haven't gone</u> into a great discussion about this. (..)</p> <p>[The children] haven't raised [the AD] (...) I think I am <u>inclined not</u> to. (.)</p>	<p>K: absent</p> <p>P Sub</p>
Andy	<p>Like I say people, in this country don't talk about sex and death so.</p> <p>It's difficult because you, on the one hand you don't want to make too much of it. Ehm, you don't want to go to your friends and start <u>ramming it down their throat</u>, this sort of thing.</p> <p>Oh, it's just like the Julie Walters film. You know some of them 'I don't even want to talk about it, no, <u>'go away, don't talk about it in front of me'</u>. Other people, who are no problem and entirely agree.</p> <p>Well, we mention it but, you know, we get a reaction we don't mention it again sort of thing, you know.</p>	<p>P</p> <p>Sub: the eu/as person</p> <p>P</p> <p>P</p>
Liz	<p>Is it embarrassment? Is it that I'm <u>frightened of upsetting</u> them? Ehm, must be something <u>holding me back</u>. I don't know, no time perhaps, don't know who to go to first? Ehm, waiting for the right moment, I don't know. It must be one of those I suppose.</p> <p>I think it is going to be difficult but not for the way that I think it will ehm 'oh, absolute rubbish' I eh think <u>he'll just pass it</u> off eh don't think he will <u>want to talk</u> about it somehow.</p> <p>Yes, yeh, but I think well I have a friend who is dead against it and <u>she just will not enter</u> into any conversation about it at all. Ehm, I said to her 'you know we'd like people at the group, that feel as you do'. 'No, you won't change my mind'. 'No, I don't want to change your mind but you know, it would</p>	<p>P</p>

	be nice for us to hear your points of view' but anyway.	
Violet	<p>And even with the unlike minded group who are open to talk, is very wonderful and that is very necessary as well. It's ooh [in the Quaker group] whereas if I said that to some other friends of mine they would be '<u>heee don't talk about, don't think about it</u>'.</p> <p>And then there is also the the church view, people who are quite clear we don't think about that because <u>it's not for us to discuss</u>.</p> <p>[The headmaster] would say to these kids 'the one thing that is certain is that we will die' and I'd think 'you can't say that to ten year olds and twelve year olds', but he did and it was fine (slaps table). It became a normal thing and that was very very grounding for me as well.</p> <p>Being able to explore these ideas with a <u>like minded group</u>. And even with <u>the unlike minded group</u> who are open to talk, is very wonderful and that is very necessary as well.</p> <p>I don't, I see my, I see one son once a year or twice a year for very short times, and the other maybe once every two years. One lives in [NAME] and the other works overseas. We, <u>we can't talk about this every time we meet</u>.</p> <p>I suppose this it to do with the culture that we're <u>so separated</u> from death and so separated from it being a reality of life.</p>	<p>Sub: talking Quaker P</p> <p>P Sur</p> <p>P: institution</p> <p>P: institution</p>
Ester	No, <u>I don't talk it about to people</u> . I mention about the group like that to [NAME], but there is nobody really close other than that that I would do it to. Cause <u>you've got to know the people well</u> .	

Rationality

Beth	I just think it is absolutely <u>ri ridiculous and appalling</u> that people, who really want to die, should be made to suffer because of somebody else's views.	P
Ellen	Well, I don't think I am looking at it <u>emotionally</u> . To me: <u>practicality</u> .	

<p>Andy</p>	<p>I, I, it annoys me when <u>I see intelligent, more intelligent people</u> than I am, eh, more capable than I am, eh not wanting to talk about it. But the law eh law is real ass, because you look what's happened. There is a goodly number, I can't remember the figure now, but there is a goodly number of people who've been to Switzerland, and its illegal to assist somebody to commit suicide. But the law hasn't, hasn't taken any measures against those people that assisted those people to go to Switzerland. <u>So what is going on here?</u></p>	<p>K</p>
<p>Violet</p>	<p>Ehm law that more that people's rational and views are respected.</p> <p>[The GP] talked me through it very sanely, very encouragingly and made it ordinary.</p> <p>Our <u>own emotions</u> might well sort of step in and take away from this that we're trying to <u>be rational</u> about. <u>I'm clear and rational about my choice, I don't understand</u> why it should be not given not not permitted</p> <p>The <u>emotive counter argument</u> is that lots of little old ladies will be persuaded against their wills</p>	<p>P Not Sub</p> <p>P</p> <p>P Sub: old ladies</p>
<p>Ester</p>	<p>And we don't get <u>an equal say</u>, proportionate to what I would suspect the numbers are who want it. And I would also suspect that most people don't really begin to think about this topic.</p> <p>The <u>law must accept</u> that for those that want it, it should be there. The others don't have to do it. Why, if they don't want it, should they stop us. <u>That isn't logic either.</u></p> <p>Vociferous strong voice is might be small, but it tends to <u>monopolize</u>. <i>Rather more than that.</i></p>	<p>P</p> <p>P: small minority</p>

Appendix 3.1 BBC 4 Thought for the Day, 17 February 2011

Rev. Angela Tilby

Retrieved from:

<http://www.bbc.co.uk/religion/programmes/thought/documents/t20110217.shtml>

This week's report from the Health Service Ombudsman about the [care of the elderly](#) is in a long line of criticisms about the way older people are often badly treated in hospital. She cited appalling examples of neglect, pain and lack of dignity. The Head of Nursing at the Royal College of Nursing said, "We need to understand why this is happening and why dignity is not being promoted".

Later on television I saw student nurses being reminded that each patient is an individual to be treated with respect. I suppose the question is, how does this get forgotten? It is not simply a matter of overwork and understaffing, not just a problem to be fixed.

There's something deeper going on at an emotional level which needs to be addressed. I had a conversation once with a very elderly and frail priest who said that his daily prayer at this time of life now came from the 71st Psalm: "Do not cast me away in the time of old age; forsake me not when my strength fails".

That is a prayer to God, but it could be a plea to a family, to a nurse, to the staff of a care home. There is something in us which is frightened by the sickness and weakness of the elderly and would rather look away. The deterioration of the body and the distress of the mind hurt us. We revolt against it. This is such an instinctive response that traditional societies have worked hard to counter it; to insist that the aged are treated with respect and

deference. But that is less so with us. Perhaps, we are becoming less civilised, less tolerant. Many of our nurses and care staff are brilliant; both professional and kind. But when we hear those stories of neglect and suffering isn't it likely that those responsible are simply overwhelmed by their own anxieties, and try either to avoid or to hit out at the cause? It is not enough to blame them.

What is needed here is *praeparatio mortis*: preparation for death, a spiritual education in coming to terms with our mortality. This is a task, not for the last weeks of life - it is often too late by then - but for much younger people and especially for those who care for the frail elderly. What happens to them may happen to us; if we care for our own souls and bodies we should treat the infirm with love. It may sound brutal but there's no point in caring for such people if you have not learnt to accept and then to overcome your own fear and revulsion. There is a point in preparing for death; it civilises us and brings us to count our own days with thankfulness. As I come towards the end of my 61st year I don't want to have to agree with The Who that "I hope I die before I grow old".

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Appendix 4		Word Count Statement		
Thesis Abstract				
	469			
Literature Review				
Abstract	159			
Main text		6 173		
References			1 669	
Total				7 994
Empirical Paper				
Abstract	247			
Main text		7 865		
Table		(128)		
References			1 362	
Total				9 474
Reflective Paper				
Main text		7 167		
References			1 239	
Total				8 334
Total		21 205	4 270	
Appendices				
Appendix 1	5 109			
Appendix 2.1	24			
Appendix 2.2	333			
Appendix 2.3	11 083			
Appendix 2.4	5244			
Appendix 3.1	524			
Total		22 317		
Total				47 792