

**Understanding The Experiences of People Who Are
Considering Ending Their Lives by Assisted Dying: An
Interpretative Phenomenological Analysis.**

Portfolio Volume 1: Major Research Project

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List of Abbreviations

AD	Assisted Dying
AED	Advanced Euthanasia Directives
BMA	British Medical Association
BPS	British Psychological Society
DiD	Dignity in Dying
GMC	General Medical Council
GP	General Practitioner
HCP	Healthcare Professional
HCPs	Healthcare Professionals
HCPC	The Health and Care Professionals Society
HIV	Human Immunodeficiency Virus
IPA	Interpretative Phenomenological Analysis
MAID	Medical Assistance in Dying
MeSH	Medical Subject Headings
PICO	Population, Intervention, Comparison and Outcome
PRISMA	(Preferred Reporting Items for Systematic Reviews and Meta-Analyses)
RCP	Royal College of Physicians
PAS	Physician-assisted Suicide
SLR	Systematic Literature Review
UK	United Kingdom
US	Unbearable Suffering

Abstract

Assisted dying (AD) is currently illegal in the United Kingdom (UK). Despite this, people from the UK are travelling abroad to organisations in Switzerland, such as Dignitas, in order to complete an assisted death. To be accepted by Dignitas an individual is assessed by a physician and has to either have a terminal illness or be experiencing unbearable suffering and must have capacity to make the decision to complete an assisted death. Although there has been a range of research conducted in countries where AD is legal, little is known about individuals in the UK who travel abroad to access AD.

This study sought to explore the experiences of individuals based in the UK who were considering travelling abroad for an assisted death. This was achieved through the Interpretative Phenomenological Analysis (IPA) of six participants following semi-structured interviews. Four core themes were identified: contemplating death, dying, and assisted dying; a desire for an honest and open discussion regarding AD; experiences of suffering and deteriorating health; and, the importance of autonomy and control.

These findings show that people considering AD are experiencing a wide range of suffering related to their deteriorating health and are worried about the impact this will have on their future lives. Participants felt they had to hide parts of themselves from HCPs due to being unable to talk about their desire for AD. Participants wanted to be able to have autonomy and control over the manner of their death and knowing they could pursue AD brought them comfort. Professional governing bodies can do more to provide training and guidelines to allow HCPs to both support the suffering associated with a request for AD and also to act within the legal framework of the UK.

Introduction

This chapter will begin by situating the researcher and providing their ontological and epistemological position in relation to this research project, followed by their personal relationship to the project and will provide a discussion on the language used in this report. The chapter will explore the current context of the global AD debate and research. It will then focus on the UK context, looking at the legality, public opinion, the current position of relevant UK professional bodies towards the topic and provide a broad overview of the existing research literature about the experiences of people considering AD.

Situating the Researcher

Ontological and Epistemological Position

The ontological position that is taken by the primary researcher in this project is one of a critical realist. Critical realism states that there is an objective reality ‘out there’: A natural world that is governed by laws independent of the human mind (Bhaskar, 1993). However, the ‘critical’, in critical realism, notes that it is difficult to access this natural world. It includes a belief that social processes cannot be reduced to natural laws. Research is therefore a human activity, one that is mediated through language and social structures (Gorski, 2013). The realist may hold the belief that there are some underlying natural laws beyond the subjective and social processes which can be accessed, and that these are more ‘real’ and exist outside of the researcher’s attempts to investigate them (Pessu, 2019). Therefore, a realist researcher may use experimental methods in an attempt to remove as much of their bias as possible in order to access the world as it truly is, and they might, further, claim that the results of their research accurately represent this objective world. However, a critical realist position was taken for this project because it acknowledges that subjective processes, i.e. the human experience, cannot be reduced to natural laws. It allows

for the recognition of the human element of interpretation on the part of the researcher and is aligned with qualitative research methodologies .

The epistemological position of the primary researcher is phenomenological. Phenomenology was first developed by Husserl (1859 – 1938) and focuses on the study of human experience (Husserl, 1989/2012). It rejects the claim that there is something behind the experience, or more fundamental than the experience itself (Smith, 2015).

Phenomenology acknowledges that in qualitative research, the participants are interpreting and making sense of their own experience and the researcher is then engaging in another level of interpretation, as they attempt to interpret and make sense of the participants' experience. A process known as the double hermeneutic (Smith & Nizza, 2022).

Personal Relationship to the Project

Due to the potentially contentious nature of the discussion related to AD and due to the qualitative nature of this research, it is important that I declare my personal relationship to this project and any factors that may be influencing my perspective. I was brought up in a secular household and do not have a religious affiliation, being agnostic in my belief towards the existence of any God. I also hold a humanist perspective towards questions of morality, ethics, and human wellbeing. Further to this, I also live with a chronic illness. These factors have likely influenced my interest in and attitude to this topic, but I have attempted to bracket these personal perceptions and attitudes throughout this project in order to reduce their impact on this study.

I had been interested in the topic of AD for many years before starting this project. I was intrigued by the moral and philosophical argument around an individual's right to autonomy and to self-determine. This seemed to me to be prevalent in many aspects of life, but this belief in autonomy did not appear to translate so readily to the discussion about AD

in the UK. My own personal experience of loved ones going through painful and difficult deaths had made me question if there was another way to approach death and dying.

The public debate around AD in the UK seemed to me to be controlled by people who were not, themselves, going through difficult and painful experiences related to incurable illnesses. I wondered what the experiences were like for those travelling abroad for AD under the real risk of prosecution. What were their motivations for considering AD? How did they reach a conclusion that AD was a better option than to die in the UK? I also wondered how I would respond if an individual raised a request for AD in my clinical practice. How would I navigate the legal and therapeutic issues this might raise? As a clinical psychologist in training, the therapeutic work I engage in is often about having difficult conversations, attempting to bring the unsaid into the realm of the said and this research topic seemed to be a continuation of that work.

I do not write this project as an attempt to convince the reader of the morality of AD but as an endeavour to further our understanding of the experiences of people considering AD and to give them an opportunity to have their voices heard.

Terminology and Language

AD can cover two methods of assistance in dying: Physician assisted suicide (PAS), during which the patient administers a medicine provided by a physician; the second, is voluntary euthanasia during which the physician administers the fatal medication. This research project will use the term AD to refer to the first method of AD mentioned above. AD was the preferred term by all the participants in this study to describe their situation. The kind of AD participants referred to in the present study was an assisted death in Switzerland with an organisation such as, Dignitas. Dignitas provides the lethal medication to the patient, but the patient must be able to take the lethal dose themselves.

Throughout this study I have used the word ‘patient’ to describe individuals who are seeking AD. This was for several reasons, firstly, in countries where AD is legal, it is usually physicians who oversee the AD clinics, as such the existing research refers to individuals as patients. Secondly, most people considering AD are also experiencing chronic, life-limiting illness, and as such, are under the supervision of medical teams or palliative care for treatment and are, by definition, patients. I am aware that there can be some negative connotations with the word patient, but there are also difficulties with other words such as client and service-user, and patient can be the preferred word used by individual’s accessing services (Ritchie, 2000).

The majority of this report is written from the third perspective in order to centre the voices of the participants and the research itself. However, when discussing issues related to personal reflections, the report will change to the first-person to emphasise the personalised nature of these statements.

Current Legal Status of Assisted Dying Worldwide

Switzerland became the first country to change its laws on AD when it decriminalised medical assistance in suicide in 1942. From the 1980s onwards, the Swiss law was interpreted to allow organisations to be created that supported people to complete their AD requests and this included foreign persons. Organisations such as Dignitas provide AD for people from around the world. These organisations assist their members in dying after a physician has confirmed the individual has capacity to make that decision, they are suffering from a terminal illness, have a life limiting disability or experience a form of unbearable pain (Burkhardt & La Harpe, 2012). Euthanasia, where a physician injects the lethal medication, is still illegal in Switzerland. Switzerland has seen a tripling in the number of deaths from AD between 2003 and 2014 with 1.3% of the total number of deaths being by AD. Of those deaths, 80% occurred in individuals aged between 65 – 94 years old (Steck et al., 2018).

Switzerland is one of the few countries that allows foreigners to travel there for the purpose of AD. The Netherlands legalised AD in April 2002 and it represents a total of 3.6% of total annual deaths (Emanuel et al., 2016). Belgium legalised AD in May 2002. The Dutch and Belgian laws differ to Switzerland, as a patient does not have to have a terminal illness and the right to AD has also been extended to those experiencing mental health difficulties. There are some cases where this has been extended to those below the age of 18.

AD is still illegal at the federal level in the United States of America. Oregon was the first state to legalize the practice with the Dignity Act in 1997 and is one of 10 states (California, Colorado, District of Columbia, Hawaii, Montana, Maine, New Jersey, Oregon, Vermont, and Washington) that have legislated for AD (Humanists UK, 2021). These states require that the patient is: 18 years or older; a resident of the state; has capacity; and, is diagnosed with a terminal illness that will lead to death within six months. In Canada, Quebec legalised AD in 2014, with the Canadian federal parliament passing legislation that legalised both euthanasia and Physician Assisted Suicide (PAS) in 2016 (Emanuel et al., 2016). New Zealand and Australia have recently legalised AD for those with a terminal illness. AD, in any form, remains illegal in the majority of the countries world-wide (Humanists UK, 2021).

UK Context

AD remains illegal throughout the UK, with individuals who assist in the death of another person facing potential prosecution under the Suicide Act (Suicide Act, c.60, 1961). The first challenge to the UK law on AD was put forward by Lord Ponsonby, in 1936. In more recent times, there have been several challenges to the current legislation. Between 2003 and 2004 the Labour peer Lord Joffe created bills in an attempt to legalise AD. However, this was rejected four times by parliament. Labour peer Lord Falconer's AD bill (Hansard, HL Bill, 6 June 2014) aimed to understand how the law could be changed and to

develop a knowledge of the conditions under which AD could occur. However, this bill suffered a series of defeats in parliament before it failed due to the dissolution of parliament. In 2015, an amendment to Lord Falconer's bill, the Assisted Dying Bill, was defeated in the House of Commons by 330 votes to 118. In 2016 the bill was reintroduced, but parliament was closed before the bill was read. As well as political advocacy for a change into the law, there have been notable attempts made by individuals who are suffering from illnesses to challenge the UK law, with some taking this to the European Supreme Court, including Noel Conway, a retired lecturer experiencing motor neurone's disease (MND) (Bowcott, 2018).

Due to the legal situation in the UK, there has been increased focus in the media of Britons travelling to Switzerland to receive legal AD, which has been named rather crassly as 'suicide tourism' (Richards, 2017). The organisations that offer AD in Switzerland are often not-for-profit, private, organisations. The most notable of these is Dignitas, where the first reported Briton completed AD in 2003. Between 2012 and 2016, UK membership with Dignitas rose by 39% to 1139 and in 2016, the equivalent of one person, every eight days, died at Dignitas. Thirty-three British people had an assisted death with Dignitas in 2022. There are currently 1,528 British members of Dignitas (Dignity in Dying, 2023).

Position of UK Professional Bodies

The position of the governing professional bodies in the UK are varied, with some taking positions on AD and providing information on how to navigate AD, while others do not. The Royal College of Physicians (RCP) conducted an online poll of their members and changed their position from being in opposition to changing the law to a neutral stance towards AD (RCP, 2019). The General Medical Council (GMC) states that doctors should discuss a patient's request for AD and provide medical records when a participant requests them for AD but further states that providing medical reports or letters in support of AD may

result in their fitness to practice being questioned (GMC, 2015). The British Medical Association (BMA) states that their members should not offer or agree to provide medical reports if they know they will be used by patients to access AD (BMA, 2015). The Royal College of General Practitioners and The Royal College of Physicians do not provide any explicit advice on how to interact with patients discussing AD.

Little guidance has been given by the Healthcare and Care Professionals Council (HCPC) and the British Psychological Society (BPS) when working with issues of AD within the UK. Despite this lack of guidance, clinical psychologists are encountering work with people who want to discuss the ending of their own lives by AD (Ricou & Wainwright, 2018). This can be a more prominent aspect of work for those working with people experiencing terminal and life-limiting illnesses.

Public Opinion

Surveys in the UK have put public support for AD between 70% to 82% between 1984 and 2005, with the figure remaining stable over that time (Clery et al., 2007). A more recent, and the largest poll to date, commissioned by the leading campaign group Dignity in Dying, put UK public support at 82% for changing the law related to AD (Populus, 2015). Fifty-three per cent of people would consider AD in Switzerland if they were terminally ill. Of the people polled, 66% stated that they would break the law and help a loved one with AD in Switzerland, 82% felt that if someone was considering AD, they should be able to discuss this with their doctor and 77% would like AD to be legal in the UK, as long as there were legitimate safeguards in place. There have been some criticisms aimed at the survey data on the topic of AD. The framing of the survey questions can influence the way that people respond, if AD is framed positively, it is more likely to be supported. Therefore, the polling data may not be accurate (Magelssen et al, 2016). Further to this, support for AD can be high

for one question but can then drop significantly when a question is asked about whether a GP should be allowed to administer the lethal medication.

Arguments For and Against Assisted Dying

The legal, moral, philosophical, ethical, and clinical debate around AD is complex and nuanced (Fontalis et al., 2018). An in-depth exploration of this debate is beyond the scope of the current project but a very brief overview of some of the pertinent arguments are described for context. The belief in patient autonomy and the right of an individual to determine their treatment is a leading argument for AD. The argument from autonomy states that an individual should be able to make an informed choice, free from coercion, even if that choice results in their death. AD is seen as an opportunity for the patient to preserve their dignity, have some control over the manner of their death and avoid unnecessary suffering (Rodriguez-Prat et al., 2016). However, there are some who argue that an individual never has complete autonomy. Autonomy is relational, being shared among the patient's support network and HCPs (Gómez-Vírseda et al., 2019). An often-cited counterargument to autonomy is that of the 'sanctity of life', the belief that life is of the highest value and preserving life triumphs all other values, including autonomy. This argument has often been associated with a religious framing of the debate, notably that God is the only one who can decide when someone dies. Therefore, no one is permitted to bring an end to a life prematurely (Baranzke, 2012).

Another argument posited against AD is that of the 'slippery slope': once countries legalise AD, a slippery slope develops where more and more people become eligible for, and die from, AD, with the most vulnerable in society most likely to fall victim to this. Although the number of deaths by AD in Holland and Oregon have increased over the years, there is no evidence to suggest there is a slippery slope occurring, with no findings that the most vulnerable are overrepresented in AD (Battin et al., 2017).

A further argument against AD is that society should provide better medical treatments and higher quality palliative and social care. There is a belief that improvement in these services would remove, or at least reduce, the need for people to seek AD. Striving for better treatments and higher quality of care is always important. However, research into AD often finds that patients are seeking AD for many reasons, with the kinds of suffering that medical interventions and social care can help to reduce only being a part of a wider range of difficulties (Dees et al., 2011). The Hippocratic Oath, a belief to 'do no harm' is often viewed as being in conflict with AD and seen as a stumbling block to physicians supporting AD. There are also concerns about the impact that delivering AD may have on those HCPs involved, as well as how this may conflict with their personal values (Sears & Stanton, 2001).

Why do People Pursue Assisted Dying?

Systematic reviews exploring the experiences of patients who are requesting AD often find similar motivations which include the following key themes: the impact the illness has on their quality of life; loss of functioning; loss of sense of self; fear of becoming a burden; feeling the loss associated with no longer being able to do the things they used to enjoy; physical pain and suffering associated with illness and medical interventions; anticipatory fear about how their illness will progress; and, unbearable suffering (Dees et al., 2010; Hendry et al., 2013; Rodríguez-Prat et al., 2016). As well as factors associated with their decline in health, individuals considering AD often report the concept of autonomy as being important to them. This autonomy includes a desire to maintain control over their illness and to be active participants in choosing the manner of their dying and death. A reduction in functioning that accompanies illness deterioration is often associated with patients feeling like they are losing their autonomy and that they are becoming dependent on others (Rodríguez-Prat et al., 2016). AD is seen by patients as an opportunity to have their

individual wishes respected, reduce their suffering, and maintain their dignity (Wilson et al., 2000).

The etymology of the word euthanasia stems from the Greek ‘eu’, which translates as good and ‘thanatos’, which means death. The concept of a ‘good death’ has been well explored in palliative care research (Meier, 2016), was a key part of the early hospice movement (Emanuel & Emanuel, 1998), and is discussed widely in end-of-life care research and policy more generally (Borgstrom, 2020). The concept of the good death has been defined as a “peaceful and dignified death, free from pain and other distressing physical symptoms” (Cottrell & Duggleby, 2016, p. 687). However, there is much debate about the definition of a good death, and research finds that the definition differs between patients, HCPs, and carers, suggesting that the notion of a good death is individualised (Cottrell & Duggleby, 2016).

Assisted Dying Research in the UK

The majority of research into AD is conducted in countries where AD is legal. As such, there has been very limited research conducted to understand the experiences of people in the UK who are considering AD abroad. To the best of the researcher’s knowledge, at the time of writing the current study there was only one peer-reviewed paper on this population. This study spoke to people in Scotland, who had a desire to travel to Switzerland for AD (Richards, 2017). They found that individuals were hoping AD would allow them to transcend their current and future suffering. They preferred the method of death provided by AD over the possible self-deliverance methods available to them to commit suicide in the UK. They viewed AD in Switzerland as more ‘natural’ and participants had arrived at the realisation that there would come a stage when their life would be unliveable for them.

A report published by the campaign group Dignity in Dying (DiD) called, ‘The True Cost. How the UK Outsources Death to Dignitas’ (DiD, 2017) looked at a range of

experiences of people considering AD, their family members, and their experiences of HCPs in the UK. DiD are one of the leading campaign groups aiming to change the law in the UK. They believe that anyone with a terminal illness, who has less than six months to live, should be able to access AD in the UK. Participants in this report were concerned about accessing AD abroad and the various issues that might arise from that, including fear of prosecution for them and their family members. Many of the participants interviewed for this report stated that they had received a good level of care and they were seeking AD because their life had become unliveable, as there were no effective treatments for their illnesses. This report highlighted that the average cost of obtaining an assisted death overseas was £10,000. Added to this, those who sought AD reported receiving mixed support from HCPs and were provided with wildly differing advice (DiD, 2017). These studies have aimed to give voice to the “notable minority” (Chapple, et al., 2006) and have provided some illumination on the experiences of people considering AD.

The SLR of the current study will answer the following question: What does the empirical literature tell us about the experiences of people who are considering an assisted death?

Systematic Literature Review

This chapter describes the SLR that was conducted for this research project. This will include a description of the search strategy, the inclusion/exclusion criteria, how the papers were screened, and the critical appraisal of the included studies. Following a synthesis of the relevant literature, conclusions will be drawn to inform the empirical research that follows.

Literature Search Strategy

The primary focus of this SLR was to understand the experiences of adults who are considering AD. To conduct this search, search terms (Table 1) were selected based on the Patient, Intervention, Comparison and Outcome (PICO) strategy (Santos et al., 2007) using both controlled (i.e., Medical Subject Headings (MeSH) terms) and uncontrolled terms (e.g., synonyms or descriptors) to ensure the relevant topics were covered. The PICO strategy is a commonly used framework to identify the different components of the clinical evidence for a systematic review. MeSH terms are a controlled and standardised thesaurus vocabulary that are used when indexing articles on PubMed. Search terms were selected based on the researcher's familiarisation with the relevant literature in the area and extraction of terms from previous published reviews conducted in the area.

The SLR search was conducted in May 2023 and the following bibliographical databases were used: PubMed; EBSCO; MEDLINE; EBSCO; CINAHL; and, APA Psych Articles. These databases were chosen due to their accessibility through the University of Hertfordshire (UH) library and because they covered the relevant medical, psychological, nursing, and social work journals that publish literature related to AD. The advanced search functions were used on each of the databases, using MeSH terms where appropriate (PubMed / Medline). No filters were used on any of the databases. This did result in some articles related to non-human subjects, but it allowed articles to be excluded at the screening stage rather than miss potential research that had not been labelled correctly.

Table 1*Search Strategy Used*

Focus and	Search Terms
Population: Assisted Dying	<p>“Euthanasia” OR “euthanasia assisted suicide” OR “voluntary euthanasia” OR "physician assisted suicide" OR "assisted dying" OR "assisted death" OR "assisted suicide" OR "physician-assisted suicide" OR "physician assisted dying" OR "voluntary active euthanasia" OR "right-to-die" OR "right to die" OR "medically assisted dying" OR "medically assisted death" OR “MAID” OR "death with dignity" OR "accompanied suicide" OR "wish to hasten death" OR “Wish to die” OR “hasten death” OR (Euthanasia/Psychology [Mesh]) OR (Euthanasia, Active, Voluntary [Mesh]) OR (Euthanasia/Psychology [Mesh]) OR (Euthanasia, Active [Mesh]) OR (Euthanasia, Passive[Mesh]) OR (Suicide, Assisted/Psychology[Mesh]) OR (Suicide, Assisted[Mesh]) OR (Right to Die [Mesh])</p>
(AND) Population: Patients	<p>("Patients"[Mesh]) OR ("Disease"[Mesh]) OR ("Illness") OR ("Patient*") OR ("Disease*") OR ("Condition") OR ("Chronic") OR ("Life Limiting") OR ("Client") OR ("Service User")</p>
(AND) Outcomes: Subjective Experiences	<p>(“Experience*”) OR (“Phenom*”) OR (“Perception*”) OR (“Feeling*”) OR (Reflect*) OR (“Perspective”) OR (“Understanding”) OR (“Attitude”) OR (“Opinion”) OR (“View”) OR (“Qualitative”) OR (“Lived Experience”)</p>

Search terms used in the bibliographic databases and medical subject headings for PubMed

(MeSH)

The initial database searches produced a total of 5563 papers for review. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Page et al., 2021) flow diagram (Figure 1) summarises the stages of the search strategy. The results from each of the individual databases were downloaded and then uploaded to Covidence (Covidence, Version 2), where 1882 duplicates were automatically removed.

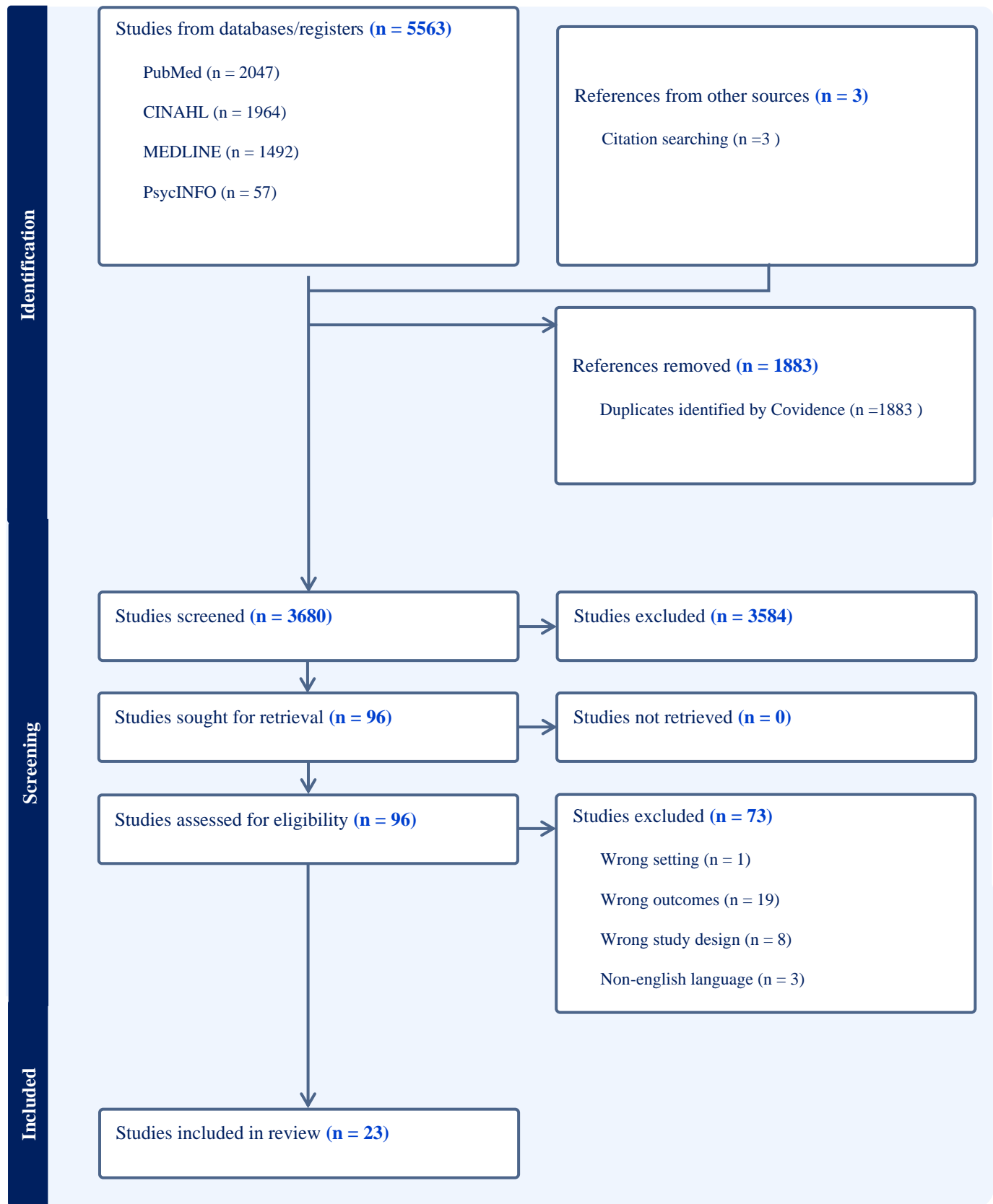
Inclusion and Exclusion Criteria

Table 2 presents the inclusion and exclusion criteria used to screen papers for this SLR. Based on the previous systematic reviews around AD (Hendry et al., 2013; Rodríguez-Prat, 2016) and in line with the ontological and epistemological position of the researcher, this review focussed on qualitative research only. Quantitative research on AD was excluded due to its inability to communicate the depth of experience of individual's considering this decision. Added to this, an initial review of the literature had shown that the majority of quantitative research was concerned with general attitudes towards AD and presenting ethical/medical scenarios to HCPs. This current review focussed solely on research conducted with people actively considering AD. Therefore, any research asking about general attitudes, public opinion, or more general experiences towards the end-of-life were excluded unless the participants were explicitly considering AD. Studies looking only at family members, carers, and clinicians' experiences have been excluded as the current study was interested in the experiences of individuals themselves who were contemplating AD.

-

Figure 1

PRISMA Flow Diagram of Systematic Literature Search



Overview of Findings

Following screening of titles and abstracts, 3584 studies were excluded, leaving 96 studies for full text review. Upon full text review, 73 studies were excluded, leaving 23 papers for inclusion in the final literature review. The reference lists were checked of the included 20 papers, and three further eligible studies were found. See Appendix A for a summary of all the studies included in the SLR. All the studies included were qualitative, with in-depth interviews being conducted with individuals who were actively considering AD, across a range of clinical settings and in countries where AD was both legal and illegal. A range of different methods of analysis were used including, thematic, interpretative phenomenological, grounded theory and inductive thematic coding. Most of the studies were conducted in medical settings with patients with chronic or terminal illnesses, with three studies looking at psychiatric illnesses.

Summary and Critical Evaluation of Papers

The quality of the research was assessed using The Critical Appraisal Skills Programme (CASP) for Qualitative research (CASP, 2018) and Yardley's (2000) criteria for qualitative research. The CASP checklist is a widely used tool for assessing the quality of qualitative research and is recommended by the Cochrane Qualitative and Implementation Methods Group (Majid & Vanstone, 2018). Appendix B shows the papers included in the review against the 10 CASP criteria. All the studies included were published in peer-reviewed journals with ethical approval gained from academic or healthcare institutions. The studies were of good quality for the following CASP criteria: setting out a clear aim for the project; the qualitative methodology being appropriate for the study; having a research design that addressed the aims of the research; and data collection consistent with the aims of the studies and the way findings were reported, leading to all studies being classified as 'valuable'.

Table 2*Inclusion and Exclusion Criteria*

Inclusion Criteria	Exclusion Criteria
Adults actively considering an AD	Quantitative
Qualitative	Wish to hasten death but not actively considering AD
Concerned with the subjective experiences of the patients	Interviews
English Language	Case Studies
	(Electronic) Health Record Research
	General Public Attitudes Towards AD
	Clinician Based Research
	Research that does not specifically attribute findings to individuals considering AD
	Ethics or Legal Papers
	Hypothetical Vignettes Regarding AD

The CASP tool highlighted similar weaknesses across some studies in relation to the reflexivity of the researchers and the lack of consideration of the relationship between the researchers and the participants. While the majority of the studies did discuss the researcher's positionality, four studies made no mention of the reflexivity of the researcher (Dees et al., 2011; Ohnsorge et al., 2014; Pasman et al., 2009; Pearlman et al., 2005), with two studies only partially mentioning aspects of the researcher's reflexivity (Pronk et al., 2022; Richards et al., 2017). Transparency and coherence are vitally important in qualitative research (Yardley et al., 2000), with the views of the researcher playing an important role in the analysis, which in turn affects decisions about which results get reported and which do not. Despite not mentioning the researchers own position, the four studies did clearly state the different stages of analysis, aiming for consensus and triangulation among multiple researchers at each stage of analysis.

Sensitivity to the context was shown in most of the studies, with the researchers often being clinicians who worked with patients considering AD (e.g., Dees, 2011; 2013, Hagens et al., 2017; Nuhn et al., 2018; Oczkowski et al., 2021). This allowed the researchers to be sensitive to the kinds of conversations patients engaged in when requesting AD. However, all the studies included in this SLR lacked involvement from participants in the study design or analysis. Service-user involvement has been shown to be beneficial for both participants and researchers (Beresford, 2013). Studies conducted in countries where AD is illegal, such as Sperling et al (2022) and Richards (2017) may have found it difficult to ethically involve service-users but there is room for improvement for studies where AD is legal.

Commitment and rigour (Yardley, 2000) to the methods of analysis were shown in most studies, with clear methodologies stated for the different stages of analysis. Studies often provided lengthy quotes from the data to support their interpretations and centre the voices of the participants (e.g., Back et al., 2002; Ekkel et al., 2022; Pearlman et al., 2005).

Impact and importance are key criteria of good qualitative research (Yardley, 2000). Several of the studies (Sperling et al., 2022; Richards et al., 2017, Leboul, 2022) included in this SLR were conducted in countries where AD is illegal, the act of conducting their research is providing a voice to the notable minority and pushing the public debate forward. Lavery et al.'s (2001) study into euthanasia requests from people with Human Immunodeficiency Viruses (HIV), was research that provided a voice to a marginalised minority and was an opportunity for those individuals to explore the discrimination and stigma that accompanied their diagnosis in society at that time.

Synthesis of Findings from the Systematic Literature Review

The findings from the studies have been synthesised into three themes, with some studies appearing in all three themes: The first theme covers the motivations and reasons why people consider AD; the second theme looks at the assessment process for AD and the

interactions individuals have with HCPs when considering AD; and, the third theme looks at the experiences of individuals considering AD in countries where it is illegal and how that differs from those where it is legal.

Motivations for Considering Assisted Dying

Unbearable Suffering

In Holland there is a legal concept known as ‘unbearable suffering’(US) (Dees et al., 2011). To qualify for AD, the patient must be assessed by the visiting clinician to be in a situation where they are experiencing US. Although there is no formalised definition of US, it is an overarching theme that includes many different motivations for someone who is considering AD. Dees et al. (2011) interviewed 31 patients who had requested AD in Holland and identified four main kinds of suffering that contribute to US: medical suffering arising from issues related to the pain and discomfort from the symptoms of their illness and their prescribed treatments; psycho-emotional suffering rooted in personal concerns about autonomy, loss of sense of self, dependency, and mental exhaustion; socio-environmental suffering related to a loss of social status, becoming a burden to others and the mental states brought on by their illness; and, existential suffering included loss of important functioning related to activities they once enjoyed, hopelessness and feeling tired with life. The suffering of the patients interviewed in this study was rooted in their illnesses, and the symptoms, and the impact on functioning their illnesses had, as well as the effects of ageing. The suffering caused by medical issues was less important to them than suffering caused in other areas of their life.

Pearlman et al. (2005) found that some patients reported their suffering was unbearable, others that their suffering fluctuated with it sometimes becoming unbearable, further participants reported that their suffering was severe, but they were not sure if they could consider it unbearable. These distinctions highlight the complexity of the concept of

US and point to the dynamic nature of the motivations when considering AD. The fluctuating nature of an individual's illnesses can make it hard to delineate when US has been reached.

What may be one person's US, another may consider bearable.

When considering US in the context of psychiatric patients, who had requested AD in Holland (Verhofstadt et al., 2017), different themes were identified, including: medically related suffering; intrapersonal suffering; suffering related to interpersonal interaction; suffering related to one's place and interaction in society; and, existential suffering. Patients expressed a wide range of psychological symptoms related to their primary disorder, as well as more generalised psychological symptoms such as stress, shame, and despair alongside physical symptoms including pain. However, mental suffering was reported as more intense than physical suffering "as it can't be seen by anyone" (Verhofstadt et al., 2017, p. 240).

Suffering Routed in the Medical Context

Dees et al. (2011) reported that the suffering participants discussed in relation to their medical issues were broken down in to five categories: physical, cognitive, psychiatric symptoms, side effects of medical treatment and decline. Pain and fatigue were the most common symptoms, with cognitive symptoms reported to cause a great deal of suffering, "I am in pain at night, I wake up with pain and go to bed with pain. If they could take away half my pain I wouldn't be thinking about euthanasia" (Dees et al., 2011, p. 730). Another participant reported, "my brain no longer works and to me that is a part of human dignity and of unbearable suffering. I want to function normally, but I can't do that" (Dees et al., 2011, p. 730). Acute and chronic pain, chronic, nausea, incontinence, smelling wounds and fatigue were all reported by Ohnsorge et al. (2014). The discussion of the suffering rooted in illness was reported in a majority of the studies in this review (Dees et al., 2011; Lavery et al., 2021; Mak & Elwyn, 2003; Mak & Elwyn, 2005; Ohnsorge et al., 2014; Pasman et al., 2009; Verhofstadt et al., 2017; 2021). A study looking at patients diagnosed with HIV highlighted

the suffering that arose from the physical disintegration caused by the illness, “I suffered before, I suffered after. That, you have to be there to believe it. And that was when I asked for euthanasia” (Lavery et al., 2001, p. 5). On top of the pain associated with their illnesses, patient’s often report pain and medical difficulties that arise from the treatments of physical illnesses (Pearlman et al., 2004) and psychiatric illnesses (Verhofstadt et al., 2017), with both being frustrated that there are no further treatments. In Pearlman et al. (2004) fourteen of the 35 cases investigated, declared pain being a major motivator for AD, “It’s [the pain] a treadmill that I’m on; I can’t get off it, and I’ve had it. And I can’t live like this anymore” (Pearlman et al., 2004, p. 236). However, three studies reported that pain was not a motivator for those considering AD (Nuhn et al. 2018; Pasmán et al., 2009; Pearlman et al., 2005).

As their illness progressed it was the accompanied loss of functioning that motivated some towards AD (Nuhn et al., 2018; Pearlman et al., 2005; Sperling et al., 2022). Pain related to illness progression, as well as the side effects from treatment, play a role in motivating people to pursue AD, but physical pain itself is not the sole motivating factor, with the impact the illness has on functioning and other aspects of their life also important. The concept of US highlights the many different areas of suffering that can occur and shows the importance of taking an holistic approach to understand this suffering.

Autonomy and Control

Autonomy is a key factor across much of the literature reviewed that looks at motivations for considering an AD (Dees et al., 2011; Nuhn et al., 2018; Ohnsorge et al., 2014; Pronk et al., 2021; Van Wijngaarden et al., 2016; Young et al., 2021). One participant with terminal cancer stated:

I say I have made my decision. I don’t want you to treat me any longer. Someone says, now you are probably too weak for chemo. I say: If I’m not too weak and they want to give me chemo, I will refuse it, because in the little time that is left to me, I

want quality of life, not quantity of life. I decided that a year ago (Dees et al., 2011, p. 730).

Individuals in the studies reviewed asserted that autonomy included: having control over their end-of-life situation; being able to choose the manner and date of their death; self-determination; and, a desire to claim back from the illness a sense of control that they had lost (Dees et al., 2011, 2013; Nuhn et al., 2018). Nuhn et al. (2018), highlighted the importance of choice for individuals, with one participant stating ‘I don’t want [to experience the end of the illness]. I want options. I want choice. I deserve that’ (Nuhn et al., 2018, p. 383).

In Ohnsorge et al. (2014), a patient stated that they did not share the values of the medical system and felt that physicians were not respecting these values. They wanted to take back the control over the decision making from the physicians and to determine the manner of their death. It was control that was important to some, “[I]want to be able to keep this in my own hands for when the moment comes. I was a very self-determined person all my life, and that’s very important to me” (p. 8). Although not everyone in this study had an active plan for AD, there was a theme that their wish to pursue AD was about reassurance, “well, you don’t have to [go through with the AD], you can get out of it any time. But it’s more of a reassurance” (p.10). Individuals wanted to assert autonomy at a time when it appeared all control was lost, “if nothing works anymore and things are only getting worse, then you’d still have some way of shortening it” (p. 11).

In Young et al. (2021) participants asserted that they had lived independently prior to their illness and this desire for independence continued into their illness, “I guess it is just who I am” (p.4). Autonomy was also identified as a theme among psychiatric patients considering AD (Pronk et al., 2021), who felt that their right to choose should be extended to AD. Participants believed that the state should not be involved in making decisions about

their death. This research was conducted from a Foucauldian perspective and posited the ‘paradox of control’: people want to assert control over the decision to end their life, however, a medicalised version of AD puts the control back with the medical professionals, further removing control, hence the ‘paradox of control’. It is possible that the findings of this study reflect the Foucauldian approach to analysis, where apriori ideas around control and freedom are mapped on to the data rather than them being inherently obvious in the analysis.

Anticipatory Fear

Several studies reported individuals experiencing anticipatory fear about the progression of illnesses and the deterioration of functioning that would accompany this (Dees et al., 2011; Mak & Elwyn 2003, 2005; Nuhn et al., 2018; Pasman et al., 2009; Pearlman et al., 2005). The dying trajectory was described as worse than death itself by participants in several studies. Anticipatory fear was associated with potential decline in functioning, independence, relationships, and loss of community (Mak., et al, 2003; Nuhn et al., 2018). Fear for the future was reported as a main motivation in 21 of the 35 cases explored by Pearlman et al. (2004). Half of the cases stated that their anticipatory fear about the course of their death was related to observing a difficult death of a loved one, “[My mother] died of cancer, and we were constantly frustrated by not being able to do anything for her. . . And just watched her waste away” (Pearlman et al., 2004, p. 238). Witnessing the decline of a loved one influenced people’s fear in other studies too. With one participant stating, “My grand-mother, I saw her suffocate to death. And what a terrible way to go” (Leboul et al., 2022, p. 238). When participants with Huntington’s disease were interviewed regarding their advanced euthanasia directives (AED), many of them reported seeing the impact of the disease on their parents as a factor in their decision making (Ekkel et al., 2022). They worried about no longer being able to do the things they enjoyed and realised there would be a time when their deteriorating health would lead them to carry out their AED, “I am always

creative and working with my hands. Suppose at some point I can't do that anymore, that could also be a consideration for me, [...], to say I'm done" (Ekkel et al., 2022, p. 3). Another participant stated, "that I'm going to end up like a vegetable... And that's why I have my AED ready" (Ekkel et al., 2022, p. 4). In another study, (Van Wijngaarden et al., 2016) a participant struggled to live in the here and now, feeling trapped between the fond memories of the past and his anxiety for the terrifying future that faced him, he experienced 'shameful humiliation' about his anticipated further decline.

Contemplating AD allowed individuals to imagine a future where they would be free from the suffering and anxiety associated with their illness (Leboul et al., 2022). One participant stated, "euthanasia would be like 'come on, let's move on, let's forget all this violence, and abuse, and misery, and let's think about another world ... a world which might be better?'" (Leboul et al., 2022, p. 6). After participants had decided to pursue AD, it allowed them to invest more into their current life and provided an opportunity for them to discuss their situation with HCPs. It also allowed them to discuss end-of-life arrangements with their partners (Leboul et al., 2022). A further study highlighted the benefit of AD, even if participants had delayed their decision, "And I have put the procedure on hold now, but still, I know it is not far out of reach and knowing that still helps me. It is not out of reach and knowing that helps me out in the most difficult moments." (Verhofstadt et al., 2022, p. 8).

Burden

Feeling like becoming a burden to loved ones and society was a theme across multiple studies in this review (Mak & Elwyn, 2003, 2005; Ohnsorge et al., 2014; Pasman et al., 2009; Verhofstadt et al., 2017). The idea of becoming a burden can be rooted in anticipatory fear about the future but also in the present moment experience (van Wijngaarden et al., 2016).

Patients reported a desire not to harm carers with their death, a wish to end their lives soon, and hoped to reduce the burden placed on their support network (Verhofstadt et al.,

2017). This desire to reduce the burden manifested in ensuring financial and practical arrangements of their death were arranged in advance. The impact of the patient's psychiatric disorders on carers and loved ones was also a motivating factor, "while this [psychiatric illness] endures, I'm dragging him into a depression. He gets totally exhausted" (Verhofstadt et al., 2017, p. 241). A study with terminal cancer patients in Switzerland reported participants viewing their death as releasing their caregivers from the burden of looking after them, with one patient stating, "I am burdened myself; I am such a burden to others; I want to end this" (Ohnsorge et al., 2014, p. 8). They also felt that they were a financial burden to society and their loss of a serving role increased their sense of worthlessness and feelings of being a burden to others (Ohnsorge et al., 2014). These feelings were present even when patients knew they would be willingly looked after by loved ones.

Mak and Elwyn (2003) reported becoming a burden as a major fear for participants, "in the future, when I can't manage, I would feel very bothersome and very suffering... as if I'm really burdening them. I'm afraid of having others to serve me" (p. 399). In another study, the same researchers in Hong Kong (Mak & Elwyn, 2005), looked at the meaning of the AD decision: one participant felt responsible for others' suffering, "for them to see me in pain is suffering. To see the family rushing around is so suffering...that makes me suffer" (p. 345). The researchers posited that in ancient China, the sick elderly were highly esteemed and never seen as a burden, and this was still true to an extent in current times. Participants did not always feel they were a burden to close loved ones, while at the same time feeling that they should be cared for. The financial impact of the loss of function associated with their illness due to being unable to work, as well as becoming socially isolated, increased individuals' sense of being a burden (Ohnsorge et al., 2014).

Disintegration of Self

Participants considering AD often talked about a loss, or disintegration, of their sense of self, as if something fundamental about their personhood had disappeared, or will disappear (Dees et al. 2011; Nuhn et al., 2018). In a study looking at HIV patients considering AD, the loss of self was tied to: the inability to maintain close relationships; loss of functioning; loss of mobility; exclusion from their community; and, a feeling of alienation through the actions of others. With one individual stating, “I was in a situation, in a clinic where a pregnant woman was standing beside me. She looked down and saw the [doctor’s] form and screamed at the nurse ‘I’ll come back when that thing is out of her” (Lavery et al., 2001, p. 365). Participants reported the importance of feeling like they belonged, but their illness was removing this. For these patients, AD was perceived as a way of limiting this loss of self. Their loss of community was further exacerbated due to homophobia and stigmatising events in their community and family at this time. The researchers argued that if these social circumstances could be changed, then patients would be less likely to consider euthanasia. Two thirds of participants in another study stated they were pursuing AD due to how their path to dying was eroding their sense of self (Pearlman et al., 2005). This was expressed through the idea of losing their personality, or the root of their identity, “I’m existing as a dependent non-person. I’ve lost, in effect, my essence” (Pearlman et al., 2005, p 237).

A Good Death

The concept of a good death was repeatedly shown as a motivating factor in the literature of AD (Mak & Elwyn, 2005; Pronk et al., 2022; Sperling et al., 2022; Van Wijngaarden et al., 2016). It was important to be able to control the manner of their death, the location and time, as well as deciding who would be present (Nuhn et al., 2018). AD allowed participants to plan their remaining time and to arrange meetings with their loved ones. A good death was associated with wanting a dignified death, “I believe it is a dignified way to

say goodbye” (Pronk et al., 2022, p. 483), as opposed to the slow and undignified death they felt would be caused by their illness. Pronk et al. (2022) looked at psychiatric patients in Holland. The participants in this study discussed how AD was a better alternative to suicide, which they viewed as inhumane and accompanied with a great risk that their suicide attempt might not be successful. These findings were repeated by Verhofstadt et al. (2021).

Participants in Scotland, where AD is illegal, (Richards, 2017), also discussed the perspective that AD was a safe and better option to suicide, “it is better to take that step once and then it is finished” (p. 354). One of the participants felt that using the services of Dignitas would result in less judgement from God, as it was the result of a decision by a doctor and therefore a medical procedure. She was tormented by the conflict between the sin of suicide and her wish to relieve her suffering.

Literature on Patients Experiences with Healthcare Professionals when Discussing Assisted Dying

Four of the studies included in this review explored the assessment process for those considering AD. Two studies were based in Holland (Back et al., 2002; Dees et al., 2013), one explored experiences in a MAID clinic in Canada (Oczkowski et al., 2021) and another looked at the impact of the assessment procedure in adults with psychiatric conditions in Belgium (Verhofstadt et al., 2022).

Dees et al. (2013) interviewed patients, physicians, and family members within four weeks of an explicit request for AD. They identified five distinct stages in the process of individual’s considering AD: the initial sharing of the desire for AD with their physician; development of the therapeutic relationship; legal aspects of AD; preparation and performing AD; and, events following the euthanasia and closing of the case. In the early stages of decision making, participants often explored options with family members and physicians to gain a better understanding of their situation. Patients valued their autonomy being respected

and an open and honest conversation, even if their requests for AD were ultimately denied. Participants reported difficulties when they were unable to discuss their requests openly or when physicians only considered the medical motivations in their requests.

Back et al. (2002) looked at how clinicians responded to patients request for AD by interviewing patients and family members following a euthanasia request. The study design allowed them to prospectively interview patients considering AD and then conduct retrospective interviews with carers and family members following the completion of AD. They found that patients valued their interactions with clinicians regarding AD if there was an openness on the clinician's side to have discussions about it. One participant stated they wanted, "another sane adult [who could] talk in terms... that remove the taboo from the process" (Back et al., 2002, p. 1259). On the other side of experiences, one participant reported not being able to discuss AD with their clinician, which left them feeling as if they were missing important conversations. They felt their clinician was not talking about it because of concerns with the legal situation rather than exploring their suffering. Some participants recounted extreme responses from clinicians who insisted that AD was awful and the wrong thing to do. This left these patients feeling a responsibility to make their clinicians feel comfortable and ease their worries, rather than discuss their own situation. Other participants felt that a clinician's willingness to discuss AD also meant they were more likely to discuss many other aspects of death and dying and viewed the conversation as an opportunity to do this. A clinician's unwillingness to discuss this topic was seen as a missed opportunity to talk about all aspects of the patients suffering. When the manner of their death was explained, they felt relief and felt informed about AD. Patients valued the clinicians' expertise with their illness and pain management.

Oczkowski et al. (2021) interviewed 21 patients who had requested MAID in Canada and identified several themes patients felt were important when dealing with their requests

which included: patients' suffering to be recognised; the request to die be acknowledged; fear around losing capacity; potential of no longer being eligible for MAID; and, discussion about the manner, location, and time of death. The patients valued the therapeutic nature of the relationship with the physician and valued this throughout the whole process of MAID.

Verhofstadt et al. (2022) also looked at the impact of the euthanasia assessment procedure on participants in Belgium with psychiatric conditions. All participants reported that neglect of their euthanasia request had a negative impact on their mental state, leaving them feeling misunderstood and like their suffering was not being taken seriously, which in turn resulted in a few individuals considering suicide again. These findings show that if physicians are unable to grant the request for euthanasia, it does not automatically end the therapeutic relationship and still offers a space for discussion, as long as the physician is open and willing to discuss further:

With Dr [name attending physician], I can have these conversations about euthanasia about five times a year. And just that, just knowing that I could discuss it with him every time, without getting a stigma, huh? Knowing that it might be possible one day, might even be a manner that enables you to continue to live, eh? (Verhofstadt et al., 2022, p. 8).

Verhofstadt et al. (2022) discussed the need to explore a patient's euthanasia request from two perspectives. Firstly, as a possible expression of a true desire to end their life by AD. Secondly, viewing the AD request as an attempt for an individual to have their suffering recognised and understood, providing an opportunity for the HCP and their patient to explore ways of making their life more bearable and meaningful. Hagens et al. (2017) also showed that it was important for participants to be able to discuss their wishes regarding AD and not being able to do this had a negative impact on their wellbeing. A subset of their participants

had not mentioned euthanasia to their physicians for fear of interventions or in-patient admissions due to their psychiatric history.

Literature on considering AD in countries where it is currently illegal

Most of the literature in this SLR was conducted in countries where AD is legal, with participants often recruited through medical clinics or organisations associated with the process of AD. The SLR above has highlighted that there are similarities in the experiences across studies conducted where AD is legal and illegal. Below are some of the experiences unique to those conducted where AD is illegal.

Leboul et al. (2022) conducted a study in France where they interviewed 18 patients with a variety of physical illnesses recruited through palliative care units, who had requested AD with their clinicians, even though it was illegal. Participants stated that AD requests were an attempt to have their US recognised and felt their request for AD allowed them to change their relationship with their HCPs, with the patient becoming an active agent in their treatment. Participants stated that this request for AD was an opportunity for HCPs to engage in a dialogue about the patient's situation, providing an opportunity to strengthen the patient's autonomy, even if the clinicians were not able to grant the request. The patients' shifting perspectives of their care, and the trajectories of their illness, contributed to their uncertainty surrounding their request for AD. Many patients reported satisfaction with the management of their symptoms in the palliative care unit but despite this still considered AD.

Sperling et al. (2022) interviewed 11 Israelis, who were members of Dignitas, and were considering travelling to Switzerland for AD. The results highlighted the impact the legal status had on them. Participants were worried that HCPs may not accept their advanced directives concerning their end-of-life care, they believed doctors might "see this as a betrayal of the Hippocratic oath" (Sperling et al., 2002, p. 7) fearing treatment would be forced upon them. One participant stated that they were not willing to discuss their plans with

their religious doctor for fear of reprisal. They were also anxious about the impact AD, and its legal status, might have on the family members who were left behind. Individual's expressed worry about their journey to Switzerland, fearing being stopped by the police and that their failing health may prevent their journey. Others were concerned that Dignitas may reject their request. One individual discussed how they had shared their plan to go to Dignitas with their doctor and were then questioned by the police at a later date, due to their physician breaking confidentiality. Participants needed support to be able to carry out their plan to visit Dignitas, but they struggled to find this from loved ones/family members, with one person stating they had been told, "you can kill yourself if you want to, but no one will help you do so" (Sperling et al., 2022, p. 12). Participants discussed how Dignitas had strict acceptability criteria and how they were worried that they would not meet their thresholds. Further to this, they had difficulty finding doctors in Israel who would support their application. Participants told researchers that the research interview provided an opportunity for them to discuss their wishes and desires around AD. For some, this was the only opportunity they had to discuss this topic freely, as they were unable to discuss it with family members or HCPs.

Richards (2017) is the only study found in this SLR that looked at people within the UK, who were actively considering AD in Switzerland. In this anthropological study, the researcher attended self-deliverance workshops, as well as interviewing people who had applied to Dignitas. These workshops, based in Scotland, aimed to provide attendees with methods to end their own life. Whilst they did not encourage people to commit suicide, such workshops are unregulated. Participants in this study had considered taking their own life but were worried about the consequences of this if they were unsuccessful. They reported concerns for the person who may find their body and, as such, saw attending Dignitas as "*civilise[d] and certain*" and "*fool proof*" (Richards, 2017, p. 354). One participant's family had intervened to prevent her attending Dignitas due to religious reasons on the request of her

children, as they viewed suicide as sinful. Participants felt that they did not want the doctors to have control over the end of their life, and as such, the non-medical nature of the Dignitas process was appealing and fitted with their aesthetics of death. Individuals felt that they should not have to justify their suffering to HCPs as ‘unbearable’ because they knew their suffering intimately and understood when the time would be right to end their lives.

Implications for Clinical Practice and Research

As shown by this review, there is a paucity of published research on the experiences of people in the UK who are considering AD. Approximately one Briton goes to Dignitas each week and little is known about their experiences (DiD, 2017). The research included in this review has explored motivations and reasons for carrying out AD cross a wide range of domains, including medical, psychological, social, loss of a sense of self and existential. However, this research is mostly conducted where AD is legal, with participants being recruited through organisations that provide support with the AD process. If, for example, individuals must prove that they are experiencing US to be granted their request, they may discuss their suffering to researchers within that paradigm. There are similarities across most of the studies in the reasons why people consider AD. It appears from the included studies, that illnesses have similar impacts cross-culturally in terms of their effect on functioning, pain, the side effects of medication, etc. However, how people make sense of this impact is likely to differ based on the legal and cultural context within which they are situated.

As far as the researcher is aware, only two published studies have been conducted in countries where AD is illegal. They have shown that people still request AD, even when it may not be available to them. These studies have been conducted legally, with ethical approval and have maintained the confidentiality of the participants, while providing a voice to the ‘notable minority’. This research has shown the feasibility of the current study, but

also highlights a paucity in the literature on people considering AD in countries where it is illegal. This is a gap that this current study hopes to address.

Only two studies in the review approached their analysis from a phenomenological perspective, with grounded theory and thematic analysis being the main methods used. These research methods have their strengths and were congruent with the research aims of their studies. However, these research methods can sometimes lack the analytic depth that a method such as IPA can provide, due to their larger sample sizes and epistemological underpinnings. The literature reviewed showed that the experience of suffering is subjective and deeply personal, with motivations for AD differing across the participants. Therefore, a study using IPA would add depth and novelty to an under researched topic. From the literature on the experiences of people requesting AD and their interactions with HCPs, a request for AD is not only a request to end one's life but an opportunity for an individual's suffering to be recognised and a chance to explore that suffering with HCPs.

As discussed above, several of the studies included in the review did not meet the CASP criteria for discussing the relationship between the researcher and the participants. The current study is an opportunity for the primary researcher to ensure these mistakes are not repeated and to meet both the CASP (2008) criteria for reflexivity and Yardley's (2000) criteria for good qualitative research. This will be discussed in more depth in the methods section below.

Although the perspectives of clinicians were beyond the scope of this SLR, several studies discussed how HCPs assessed US, with some physicians placing more weight on physical pain than psychosocial suffering while not viewing patients suffering as being unbearable due to the activities patients were still able to undertake (Pasman et al., 2009). There appears as if there is a discrepancy between the kinds of suffering that patients and physicians feel are unbearable. On top of this, the research included in this SLR showed that

negative responses to AD requests can have a negative impact on the therapeutic relationship and the wellbeing of those pursuing AD. Added to this, physicians reported that performing AD was one of the hardest things they had to do and needed much support through this. These issues highlight the complex nature of the relationship between HCPs and patients requesting AD and the need for both groups to be supported in relation to AD. Further to this, they have highlighted the importance of conducting research on the perspective of individuals considering AD themselves. The current study will address this.

From the perspective of HCPs in the UK, there is little to no guidance or policy given by professional bodies about how to discuss these issues with patients, and little research to base guidelines on. Research that provides an opportunity for individuals to discuss their experiences regarding AD is of benefit to the participants, as well as the researchers (Sperling et al., 2022). Considering the illegal context in the UK, research on this topic will also help provide clinicians with information on how to navigate these difficult conversations in a therapeutic way, while also helping to move the guidelines and policy discussions forward to ensure HCPs can operate in a supportive professional context. This SLR has shown that it is possible to conduct ethical and meaningful research with those who are considering ending their lives by AD. This existing research has provided a good foundation for understanding the broader topic of AD, but there is a clear gap in the literature when it comes to the experiences of individuals living in the UK who are considering AD even though it is illegal.

Research Question

What are the experiences of individuals in the UK who are considering ending their lives by assisted dying abroad?

Methodology

This section will delineate the research methods used within this study, providing information on the type of qualitative analysis used and how the quality of this research was ensured. Further to this, it will describe the development of the interview schedule, participant recruitment strategy, the participants themselves, and ethical considerations.

A Qualitative Approach

This project used a qualitative approach to understand the experiences of people who were considering ending their lives by AD. It was felt that a qualitative study best answered the research question and fit the epistemology of the researcher. Qualitative research allows the researcher to get as close as possible to the lived experiences of the participants, while ensuring that a rich and detailed account of their experiences is presented (Smith, 2015). The research methodology chosen for analysis in this study was IPA.

Interpretative Phenomenological Analysis

IPA was initially developed and used within health psychology (Smith, 1996), with its three main areas of theoretical concern discussed below: the philosophy of phenomenology; hermeneutics; and, IPA's idiographic nature.

Phenomenology

Phenomenology is a philosophical discipline first developed by Husserl (1859 – 1938) that focused on the study of human experience, or the 'phenomena' of subjective experience (Husserl, 1913/1988). Husserl was interested in getting, "back to the thing's themselves" (Moran, 2000, p. 9), getting as close to the subjective experience of the individual as possible. Husserl developed phenomenology in response to scientists, who, at the time, had tended to move away from the subjective by using abstraction to create conceptual frameworks. Phenomenology rejects the claim that there is something behind the experience, or more fundamental than the experience itself, viewing an individual's experience as an

important object of study (Smith et al., 2015). Husserl did not believe the researcher is free from pre-conceived theories when they studied a particular experience of a participant and he felt the researcher should 'bracket' the phenomena being studied and try view it as separate from any preconceived notions (Smith et al., 2009).

IPA allows the researcher to understand how specific phenomena (e.g., an event, illness, or relationship) has been experienced and understood by specific people, in a specific context (Smith, 2009). People's experiences will be varied, but there is an assumption that there are universal commonalities which can include: temporality; selfhood; intersubjectivity; subjective embodiment; and, spatiality (Ashworth & Chung, 2007). Therefore, IPA allows the researcher to make comparisons across groups of individuals and to look for common themes, but this is only done after an in-depth, case-by-case, analysis has been conducted on each participant's experiences (Smith, 2004).

Hermeneutics

The act of qualitative research requires interpretation on the part of the researcher. Hermeneutics can be conceptualised as "the theory of interpretation" (Smith et al., 2009, p. 21). The process of hermeneutics is at the forefront of the methodology of IPA. Ricour (2008) discussed two kinds of interpretation: the 'hermeneutics of meaning-recollection' which is an attempt to stay close to, and present, the meaning of the participants as told to the researcher; and, the 'hermeneutics of suspicion' which is an attempt by the researcher to uncover a deeper meaning behind the mere words that are presented by the participant. Martin Heidegger (1889-1976), who was a student of Husserl, believed that we live in an interpreted world and as such, are ourselves hermeneutic. We are not seeing reality as it really is but interpreting it through our sense data, cognitions and affect. This process of interpretation may be seen by someone with a positivist epistemology as an inherent weakness in this methodology: the aims of a positivist research project is to remove as much

personal bias of the researcher as they can, to get close to the truth of the object being studied. However, IPA, and its phenomenological stance, states that even a positivist is engaging in an exercise of interpretation, and as such, the interpretative nature of research is inescapable and should be embraced. IPA research engages in a double hermeneutic: the participant is attempting to make sense of their own experiences and the researcher is engaged in their own interpretation, and sense-making, of the participant's sense making (Smith & Osborn, 2003; Smith et al., 2009).

Idiographic Nature

IPA is idiographic in its nature. Idiographic research focuses on in-depth analysis of individual experiences. Most quantitative data methods of analysis, and other qualitative methods, are nomothetic in their analysis. Nomothetic research extracts data, analyses it and summarises it so that the end results are an abstraction that is removed from the individual's involved in the research. Nomothetic methods are focused with finding trends and commonalities among participants in their research. A nomothetic study in palliative care may measure pain on a five-point Likert scale and see if an intervention on pain management reduces that score. This research may show the effectiveness of an intervention in reducing the participant's pain score, but it will not tell us anything about the subjective experience of what it means to be in pain or how that pain is experienced by different individuals within the group being studied. The aim of IPA is for the researcher to elucidate two levels of analysis: firstly, the themes that participants share, described in their own ways; and, secondly, the reader should be able to ascertain information about the participants idiosyncratic worldview (Smith, 2004). IPA still attempts to identify themes that are similar across individual co-researchers, across multiple people in the dataset, but this is only done after in-depth analysis on each case individually.

Limitations of IPA and Consideration of Alternative Methods

IPA is often conducted on the transcription of semi-structured interviews. Therefore, IPA is based on the language that participants use to describe their experiences. This raises some issues, as it assumes that participants have the language to adequately describe their experiences. It has been argued that language never accurately describes an individual's experience but instead, it is through the use of language that an individual constructs the meaning of an experience (Burr, 2015). Some researchers argue that the language participants use tells us more about how an individual talks about an experience than providing us with access to the experience in, and of itself. For others, the language a person uses precedes, and shapes their experience, and therefore different people can describe the same event with such variety (Willig, 2013). However, IPA accepts that meaning making around experiences is rooted in metaphors, narratives, discourses, etc. and that language is closely involved with all aspects of experience (Smith, 2009). The claims about the importance of language are often made by researchers with a social constructionist or constructivist epistemological position. The phenomenologist accepts the importance of language but posits that the phenomenology is the base of reality, and language only makes up a part of this.

IPA has also been criticised for focussing on re-describing the phenomena rather than engaging in interpretation of the data (Brocki & Wearden, 2006; Larkin et al., 2006). It has been argued that IPA does not tell us about how experiences come to be, why these experiences are the way they are, or why the responses vary between participants experiencing similar phenomena (Willig, 2013). However, to find out how or why these experiences occur, a researcher would still have to rely on reporting from the participant to access this information. Smith et al. (2009) have argued that IPA uses the hermeneutic, idiographic, contextual approach to further the understanding within a cultural context rather than ignoring that context.

Before choosing IPA as the method of analysis, other qualitative methodologies were considered but ultimately rejected. Narrative analysis, thematic analysis, and discourse analysis do not use the idiographic approach of IPA, and do not provide the same kind of in-depth, case-by-case, understanding of the individual's experience. IPA is often conducted with smaller sample sizes of between 5-10 participants, as this allows the researcher to engage, in-depth, with their analysis of each participant in the study (Smith et al., 2009). Approximately 35 people travelled from the UK to Dignitas last year (Dignitas, 2022) meaning the population of possible candidates to draw from is very small. Therefore, it seemed unlikely this study would be able to recruit the higher numbers needed to reach thematic saturation through a method such as grounded theory (Vasileiou, 2018) or thematic analysis (Morgan, 2000). The idea of thematic saturation is also not something that IPA aims to achieve, being interested in the analysis of individual experiences before attempting to make any generalisations. Grounded theory is often interested in creating new theory, with a focus on social processes, which necessarily involves some level of abstraction and moves the researcher further away from the phenomenology of the individual's experiences (Walker & Myrick, 2006). Foucauldian discourse analysis was also considered but it was thought that this method would be better suited to exploring how AD is discussed in the media, by the major healthcare governing bodies, and how this influences the way people talk about AD in the UK. Although this would make an interesting study, it is not the focus of this research, with this study interested in people's experiences of considering AD rather than engaging in a deconstruction of the concept of AD.

IPA is consistent with the epistemology of the researcher and is most aligned with their clinical work as a therapist, where experience and sense making is central to the process. Further to this, self-reflexivity is a skill required of a trainee Clinical Psychologist (BPS Guidelines, 2017). The skills I have gained over training have well equipped me to engage in

conversations with participants on difficult topics and to get to the essence of their experience, while being aware of my own biases and theoretical underpinnings.

Participants

IPA studies are conducted with smaller sample sizes, using purposive sampling, aiming to find homogenous samples that all share the experience being studied in a similar context. It is recommended that between four and ten participants are included for professional doctorates (Smith et al., 2009).

A total of six participants were recruited for this study. Three were recruited through adverts sent out to members of organisations that campaigned on issues related to AD in the UK. One was recruited through a social media support group for AD, another participant was contacted directly by the lead researcher based on their public writing on the topic. A final participant was recruited after the details of this study were passed on to a different researcher, who was conducting a new and similar study (Hitchcock, 2023). They provided the information sheet for the current study to anyone who declared an interest in taking part in further research.

Inclusion and Exclusion Criteria

Participants had to be based in the UK while actively considering AD in a country where it was legal. The participants had to have considered contacting an organisation like Dignitas or be actively contemplating AD. There was no time limit on when their assisted death might take place and participants did not have to be sure that they would follow through with this decision. There were no inclusion or exclusion criteria in relation to the health conditions that individuals needed to have to be part of the study. Participants had to be able to communicate in English. However, there was no exclusion criteria for how someone could communicate. The researcher was aware that individuals with difficulties communicating verbally may be eligible and, as such, participants were notified that they

were allowed to attend with a carer or communicate with aids, such as computers. However, no participants required extra support.

Participant Information

See Table 3 below for participant information. Pseudonyms were provided to participants at the transcription stage of the research.

Ethical Issues

Ethical Considerations

Ethical approval for this project was granted by the University of Hertfordshire Health, Science and Technology ECDA Ethics Committee for the School of Psychology. Protocol number: LMS/PGT/UH/04015 (Appendix C). Due to a break in the research, the researcher renewed their ethics proposal upon return to their studies so that further participants could be approached. Ethical approval was granted with the same protocol number (Appendix D).

Informed Consent

Participants were sent an information sheet (Appendix E) and consent form (Appendix F), once they expressed interest in the study. A brief telephone consultation was offered to anyone interested in the study to answer any questions that they may have about the interview. Five of the participants requested a pre-interview consultation. Participants were informed that they had the right to withdraw from the study at up until two weeks after the interview had been conducted. This allowed time for participants to withdraw their interview upon reflection. The two-week limit was enacted due to the data being anonymised once it had been transcribed and the researcher may not be able to identify their transcript.

Table 3*Participant Characteristics*

Pseudonym	Age	Gender	Ethnicity	Health related issues	Religion
Mark	50s	Male	Irish Italian	Alzheimer's	Atheist
Betty	60s	Female	White Caucasian	Motor Neurone's Disease (MND)	No Religion
Julie	70s	Female	White British	Rheumatoid Arthritis	Early Christian Pagan
Sue	60s	Female	White British	Tetraplegia	Christian, non-practicing
Debbie	70s	Female	White British	Chronic Obstructive Pulmonary Disease (COPD)	No-religion
Florence	70s	Female	White British	Bladder Cancer	Atheist

Confidentiality and Data Management

Due to the illegal status of AD in the UK, it was important that the confidentiality of the participants was always protected. Electronic consent forms were stored in a password protected folder on the primary researcher's UH secure cloud storage. Paper copies were scanned and stored electronically in a password protected folder and the paper copies were destroyed. The digital copies will be stored by the primary supervisor for five years after completion of the study. The option of verbal consent was provided for participants who had difficulty completing the written consent form. Only one participant provided verbal consent, this was recorded at the interview stage and the audio was removed from the rest of the interview and stored electronically on the primary researcher's UH secure cloud service. This will then be stored on the primary supervisors secure UH cloud storage and will be deleted five years after completion of the study.

The interviews were transcribed by the primary researcher immediately after the interviews were completed. Two weeks after each interview, all identifying information was removed from the transcript, leaving them fully anonymised. Pseudonyms were used throughout the transcription. Any text from the interview included in the results section was completely anonymised. The audio from the interviews were stored on the secure UH cloud service and were deleted once transcription was completed.

It was explained to all participants, in the pre-interview appointment, and at the beginning of the full interview, that there would be no discussion of the details of any active plans to leave the country for AD. The interviews would discuss the participants experiences of considering AD but would not go into the specific details of when, how, and if, these plans would be carried out. This was to protect the participants from the researchers having to break confidentiality. Although suicide is not illegal in the UK, encouraging someone to commit suicide is, it was important that participants and researchers were aware of the legal

context prior to the interview. No encouragement was provided to carry out AD during the interviews. The interview schedule was only interested in finding out about personal experiences related to considering AD. It was explained to participants that if they discussed active plans for AD the researcher may have to break the confidentiality of the interview, due to the current legal status in the UK. It was explained that they would discuss this with the participants before doing so. At no stage during any of the interviews were any active plans to carry out AD discussed by participants.

The primary researcher held a dual role of a clinician-in-training, and a researcher, and therefore they had an ethical and professional duty to break confidentiality, if there was considerable risk of harm to an individual or others. The HCPC is the governing body of clinical psychologists in training and qualified clinical psychologists. They were contacted prior to the research being carried out for guidance on the topic. The HCPC does not currently have a policy on AD but referred the primary researcher to their standards of conduct, performance, and ethics (HCPC, 2014). This research did not conflict with any of the guidelines around ethics, confidentiality, and risk. Confidentiality was not broken at any point in the interviews, as nothing illegal was discussed.

Participants were informed of how their data would be used, i.e., as part of the researcher's clinical doctorate research, potential publication in peer-reviewed journal and the possibility of research findings being presented at research conferences.

Potential Distress

Participants were informed they could pause the interview at any stage and were free to withdraw at any point in the interview. If emotional topics arose, the lead researcher provided space and support to help process the emotions at that time. No participants wanted to withdraw during the interviews. Following completion of the interview, participants were asked for their feedback on the interview process and a space was created to reflect on any

difficulties that may have arisen. Once the interview was finished, participants were sent a debrief sheet (Appendix G), which provided an overview of possible discomfort they may experience, normalised this discomfort and provided a range of services for participants to contact, if they were worried by their distress. Further to this, the lead researcher offered a telephone follow-up appointment to discuss any issues that may have arisen since the completion of the interview. None of the participants contacted the lead researcher to request this.

I was well prepared for any potential distress that might arise in the interviews. I had been working in mental health services for many years and was in the third year of my clinical psychology training. I had extensive experience dealing with difficult emotions, and clinical risk, in a wide range of clinical situations. My training, to date, had equipped me with the skills to contain and support participants with any issues that may arise. The supervisory team were always available for support and were also well experienced with clinical risk and research.

Data Collection

Development of the Interview Schedule

A semi-structured interview schedule (Appendix H) was developed by the principal researcher through an iterative process, with the support of the primary and secondary supervisors. The primary supervisor was an experienced qualitative researcher and a member of the clinical doctorate team. The secondary supervisor was an experienced qualitative researcher, and had published research on AD, they also worked as a GP in The Netherlands with people considering AD in Holland. The interview schedule was also developed through peer supervision in an IPA research group with fellow students. Feedback on the schedule was also sought from the first participant interviewed. The interview schedule was

developed according to the guidance for conducting IPA interviews set out by Smith et al. (2009).

The interview schedule was broken up into three sections: Part A, reasons for considering AD; Part B, impact of the legal status; and, Part C, experiences of discussing AD with HCPs. A semi-structured interview allows the researcher to follow new avenues of conversation they might not have expected prior to the interview (Smith et al., 2009).

The Interviews

Due to the small pool from which to draw participants, it was not possible to conduct in-person interviews due to geographic factors. All participants were offered the opportunity to conduct the interviews by video call or telephone call. Two participants chose online video calls and four chose telephone interviews. Five of the six interviews lasted between 50 – 65 minutes and one interview lasted 90 minutes. The opportunity to break the interview up over different appointments was offered but all participants completed it in one sitting.

Consultation with Research Participants

With the current legal status in the UK of AD, there were no obvious groups that could be contacted for service-user involvement prior to conducting this study. Once the first participant contacted me, I explained that it had not been possible to pilot the interview schedule and I would like their feedback on this as well as finding out their experience of recruitment, information sheets, the interview process, and their experience of myself as an interviewer. We agreed to proceed with the interview schedule as normal and to then spend some time after the interview exploring their experiences. This participant was involved with giving presentations on AD at various universities and healthcare training courses across England, and therefore was a good person to conduct the initial interview with. This participant offered feedback on all aspects of the process which was helpful in realising areas for improvement. For example, they felt that all the pre-interview information sheets were

useful, and the structure of the interview flowed well. However, they felt that I could have engaged in the interview more, feeling the conversation was slightly one sided. This feedback was helpful. I felt nervous in the first interview and stuck to the interview schedule quite rigidly, which affected my ability to engage fully with what was being said by the participant. I put this down to my inexperience and concerns about covering all the questions. For further interviews, I was much better acquainted with the interview schedule and was able to allow the conversation to flow more naturally. I also made sure to discuss in the introductory section of future interviews that the conversations may feel one sided due to the nature of the research process. The initial participant also had difficulty in remembering some of the longer questions due to their cognitive impairment, this highlighted to me the importance of checking in after asking questions to ensure they were understood. They reported that the interview schedule worked well and did not offer any areas for improvement on the questions. Although this is only feedback from one participant, it was helpful in improving my skills as a researcher and allowed me to become sensitive to areas of potential difficulty for future interviews.

Data analysis

Transcription

All the interview audio was transcribed verbatim by the principal researcher. Any significant pauses or emotional responses including laughter or crying, and other important non-verbal cues were noted in the transcription, as per the guidelines set out by the creators of IPA (Smith et al., 2009; Smith & Nizza, 2022).

Analysis

The transcription data was analysed using the IPA methods proposed by Smith et al. (2009) and Smith & Nizza (2022). In the beginning of the analysis, it is important to look at each participant on their own terms, free from any theoretical preconceptions. The audio

recordings were listened to, alongside the transcriptions, to acquaint the researcher with the participants experiences and brief notes regarding first impressions from the data were made.

Following this, the researcher moved on to the four stages of IPA analysis Table 4 (Smith & Nizza, 2022), with examples for each stage provided in Appendix I.

Table 4

The Five Stages of IPA Analysis (Smith & Nizza, 2022)

Stage One	The first stage involved creating a document with three columns (Appendix Ia). The transcript was placed in the middle column and exploratory notes placed in the third column on the right. Exploratory notes contain anything of interest and are the beginning of the process to try to understand what the participant is saying. The comments were divided into three overarching categories: descriptive, linguistic, and conceptual (Smith et al., 2009). Descriptive comments focus on the content of what the participant is saying. Linguistic comments focus on the meaning of the words being used and how they are spoken. Conceptual comments were often written as questions the researcher is asking of the text as they start to move away from the words on the page to more interrogative and conceptual levels of analysis.
Stage Two	This stage involved the formulation of experiential statements. Experiential statements try and uncover what has been learned about the participants' experiences, attempting to capture the psychological reality of the participant. They are meant to be dense and succinct. These were placed in the left-hand column of the transcription table and then compiled into a complete list of experiential statements (Appendix Ib).
Stage Three	The primary researcher then looked for connections between the experiential statements and began clustering them, looking for similarities and differences (Appendix Ic). These statements were then placed into a table of Personal Experiential Theme (Appendix Id), with participant quotes to illustrate the themes. A Personal Experiential Theme table was created for each individual participant, with the researcher bracketing the data and treating each case as a novel analysis.
Stage Four	The principal researcher began the cross-case analysis, where they looked for similarities and divergences in themes across the different participants, using each participant's table

of Personal Experiential Themes. This stage led to the creation of a table of Group Experiential Themes (Appendix Ie). This table shows how each individual case contributes to the development of the group themes, with quotes from participants to highlight this. The group themes provided both areas of convergence and divergence and this table was used to write up the results.

At each of the stages of analysis, and write up, the findings were discussed with the wider supervisory team. Supervision was used as an opportunity to discuss the development of individual themes and group themes, which allowed the research team to reach a shared understanding of the analysis.

Quality Assurance

To ensure the quality of the analysis in this research project, measures specific to qualitative research were used (Yardley, 2000) and CASP (CASP, 2018b). See Appendix B for a table showing this research project scored against the CASP checklist. The area of the research which was often missing in the data published in the SLR was attended to in this project: reflexivity and the impact of the role of the researcher on the participants. As well as meeting the requirements for the CASP checklist, the four major themes for good quality qualitative research (Yardley, 2000) are discussed below (Table 5). These criteria of assessment of qualitative research are recommended by the developers of IPA as useful in assessing the quality of IPA (Smith et al, 2000).

Table 5*How the Four Major Themes for Good Quality Qualitative Research Were Met*

<i>Yardley's (2000) Qualitative Criteria</i>	Evidence of how criteria were met
<i>Sensitivity to Context</i>	Writing the introduction and conducting the SLR acquainted the principal researcher to the surrounding discourses and evidence on this topic and highlighted gaps in this knowledge, showing the need for this project. The researcher was also aware of their position and influence on the participants and how that might impact what participants felt comfortable sharing. This was countered by checking in with participants throughout the interview process and ensuring the research process was comfortable for them. The primary researcher's own training as a clinician allowed them to reflect on their own personal responses and how that might affect participants.
<i>Commitment and Rigour</i>	This project has shown commitment and rigor as evidenced by the extensive time spent on the analysis of each individual case, making detailed notes, and being immersed in each interview. Ensuring the analysis is moving away from the literal, and descriptive, and engaged fully in the double hermeneutic. At each stage of the analysis, discussions about coding and interpretations were had among the supervisory team. This ensured that the themes were agreed from different perspectives, including those with qualitative research expertise and clinical expertise within the field of AD.
<i>Transparency and Coherence</i>	The lead researcher declared both their personal epistemological position, life experiences and reasons for conducting this study. They opened each stage of the analysis up for discussion with their supervisory team. Further to this, examples have been provided for each stage of the analysis to show that findings are rooted in the data. The results section will include quotations from the participants to illustrate how the themes were reached using the participants' own words. Excerpts from the researcher's reflective log are included (Appendix J).
<i>Impact and Importance</i>	This research topic is under researched in the UK and it is important that the voices of the notable minority are heard (Chapple, 2006). The impact of the research will not be known until it is published, however, the findings will hopefully illuminate the experiences of people considering AD in the UK and contribute to furthering the research in this area.

Results

This section presents the results of the IPA conducted on the six interviews in this study. Themes were created by the primary researcher in discussion with the supervisory team. The themes delineated are reflective of the interpretation made by the researcher and supervisors, but it is important to note that other interpretations of the dataset are possible. Further to this, and in-line with the double hermeneutic principles of IPA, readers will also engage in their own sense making of the results presented. This is inevitable and rooted within the foundations of this research methodology and its epistemology. The section presents verbatim quotations from the participants to support the identified themes.

Table 6 presents the five group experiential themes identified and their corresponding sub-themes. Great care has been taken to ensure that all voices are represented equally when presenting the themes.

Table 6

Group Experiential Themes and Subthemes

Group Experiential Theme	Subtheme
Contemplating death, dying, and assisted dying	Taking comfort from a possible assisted death Worries about pursuing an assisted death
A desire for an honest and open discussion regarding AD	Wanting to be heard Perception of the topic of death and dying being a taboo in the UK
Experiences of suffering and deteriorating health	Disintegration of self Witnessing the suffering of others in death
The importance of autonomy and control	Valuing autonomy and wanting control Not wanting to become a burden on others

Group Experiential Theme 1: Contemplating Death, Dying, and Assisted Dying

This group experiential theme refers to participants' contemplation about death and dying, with AD often being viewed as a peaceful alternative to the feared difficult death that awaited participants because of their illness progression and the effects of ageing. For some participants, knowing that they had the choice of an assisted death provided them with a sense of peace and comfort, even if they were not sure they would ever travel abroad to access AD. For others, knowing that they could choose AD, to avoid a death full of suffering, allowed them to enjoy their current lives more. Contemplating AD provided participants with a feeling of control and a sense of certainty when faced with the uncertain nature of their illness. For some, their hope for AD started when they were faced with a long battle with illness, for others it started when they had witnessed a slow and difficult death of a parent/loved one. This theme also represents the fears and worries that participants had about pursuing AD, especially due to the illegal status in the UK.

Taking Comfort from a Possible Assisted Death

AD was viewed by participants as providing a good death, or at least, a better death, especially when compared to the likely decline brought about by their illnesses. Florence highlighted her relief at being able to pursue AD when contemplating the likelihood that next time her cancer returned it would be terminal:

I knew if I stayed on the bus to the Terminus, then it was going to be incredibly bloody painful. I would watch my beloved partner watching me die, you know, with all the helplessness that that would bring on for him and I was you know, and it will be just so miserable... And I was enormously relieved that I could get off the bus because of Dignitas at an earlier stop. And I would choose to get off if I was in England with assisted dying, but nonetheless a huge relief that I could get off the bus before I show up to the really nasty bit. (Florence)

Florence is not only contemplating her own pain from the illness but also sees AD as an opportunity for her partner to avoid witnessing her experience that pain. Florence's use of the metaphor of travelling on a bus allowed her to convey that she is faced with a difficult journey ahead, that she is fully aware of the destination and desperately wants to avoid it. Therefore, choosing AD provides her with a choice to exit the bus when she feels ready. It is interesting that she uses the word 'Terminus' with its close similarity to terminal: the bus terminal and her terminal diagnosis. Florence wishes that AD could happen in England but knows this is not available to her. For Florence, the thought of AD allows her to avoid the 'nasty' part of the end of her illness. She projects forward in her mind, imagining the likely painful scenario that would accompany her cancer returning. It seems that this imagined pain motivates her towards considering AD, and having the choice allows her to accept, to a certain extent, her future.

For Sue, having the option of AD also provided a sense of security to avoid a likely difficult death. She used her decision as a springboard from which she was able to continue living her life in the present moment. Knowing that whatever happened with her health, however hard things got, she would always be able to escape that suffering with AD. Sue viewed AD in pragmatic terms, like paying off a mortgage, a life task that could be administered, organised, like any other task one carries out in day-to-day life. Perhaps this pragmatic, almost detached, way of talking about AD allowed her to limit the emotional weight of considering such a decision or is reflective of her pragmatic personality:

A baseline of security, it's like having, it's like having a little nest egg of savings. It's like that sort of, erm, you know, you've paid off your mortgage. It's like that sense of, okay. it's there. You know, I've written my will or whatever, it's there. I'm, I'm, I'm kind of that's organized that's sorted, I know it's there. Now get on and, get on enjoy what you can. (Sue)

Betty's experience of working with patients with MND as a nurse, and recently witnessing a friend with MND have a difficult death, had confronted her with experiences of how difficult her death from MND may be and what it may look like. For Betty, unlike other participants, her imagined future decline was rooted in life experiences of others with the same illness. Despite these experiences, she explains that she cannot predict the future and, as such, is still projecting forward to an imagined scenario where she would be ready to pursue AD:

I mean, you haven't got a crystal ball. You don't know, and I still don't know, how it's going to end for me, but I think it would be nice to know that there is, a safety net if you like, that you can go, 'actually, you know, I don't want to do this anymore. (Betty)

The thought of an assisted death seems to have allowed Betty to contemplate that, no matter how bad things might get in the future, she would always have the choice to escape her circumstances. This sense of a choice provides her with present moment relief from future imagined scenarios stating, "It feels sort of, it would feel like a safety net really, so that if I find myself in a position where your life is just, erm, painful, scary, unpleasant, not enjoyable, that, that decision is an option."

For Debbie, contemplating AD provided her with some sense of comfort, "It is there as an option. And that's enormously comforting, well enormously comforting [slight self-deprecating tone in voice] it's there... I think it does give a form of content. And peace is part of that perhaps." It seems that she recognises the magnitude of this choice of an AD being "enormously comforting" using a humorous, self-deprecating, tone to illustrate her awareness. Perhaps this suggests that some of the time considering AD provides her with relief and peace but other times she is aware of how heavy this choice wears on her mind. Indeed, it is likely that her preferred situation would be to not have to

make this choice at all. It seems that Debbie knows that AD will bring with it its own set of difficulties and anxieties but, for her, the difficulties, and anxieties around the progression of her illness are likely to outweigh them.

Worries About Pursuing Assisted Dying

This sub-theme focuses on uncertainty and worries participants had about pursuing AD. Both in the doubt surrounding their own decision making regarding completing an assisted death and due to the context of the current illegal status in the UK. There was a real worry about the legal consequences for those that pursued AD abroad and frustration about being forced to leave the country for AD. Julie stated, “It shouldn't be having to go off to a clinic abroad and you know, hope that the police don't stop you. Hope that, you've you know you've done everything right, you've filled in the forms and presented everything”. Julie was annoyed at what she perceived to be unnecessary anxieties being placed on people hoping for AD. She felt anyone considering AD already had so much to contend with. Julie continued explaining that she was aggrieved that she would potentially have to go abroad for AD before she was ready, to meet the strict UK legal requirements:

It's very true, is that you have to go before you're ready. Because you have to be able to travel there. You have to be competent. You know, you have, to have capacity. You have to be able to travel there. You have to be able to administer the medication yourself. (*Julie*)

Julie's repetition of “have to” highlights the pressure she feels about pursuing AD abroad and the difficulties associated with the journey. She is concerned that she might end up in a situation in the UK, due to her health, where accessing AD is no longer attainable for her, leaving her to face a difficult death with no way out. Perhaps these worries also highlight her frustration with the illegal context in the UK, as this adds extra and unnecessary layers, to an already difficult situation. Florence discussed similar anxieties and frustrations at

having to travel abroad for an AD. These were accompanied by a sense of unfairness at people having to go abroad before they are ready. Florence is grateful she can contemplate AD abroad but wishes that it was available to her in her own country:

The fact that you've got to go abroad, to have assisted dying, is, is, it's fantastic given that you're in country, don't do it, doesn't do it. But it's actually, you know, creates problems, timing, and all of those things that really dying, you'd rather be in your own bed and say to your doctor or your nurse, you know, or go to a clinic, however it would be done if it was in England. You know? But going, going a few miles to have it done in your own country would be very, very different from having to board planes, cross borders. And I'm sure that means that people have to go earlier than they would, which isn't really fair. (Florence)

Florence speaks to the desire for a peaceful death in her own home, which is currently denied to her. There is something alien to her about having to go to an unknown place, surrounded by unknown people. She is having to contemplate her own death, while experiencing suffering from her illness and to add all these unnecessary layers of worry on top seems pointless, or at least avoidable.

Mark was concerned for those that would be left behind once he had completed his AD in Switzerland. He felt sorry for his religious mother. Mark would have to be cremated in Switzerland and she would not get to have the funeral she desired because of the illegal status of AD. It was clear to Mark, who was not religious himself, that the symbolic nature of a funeral was important in helping those who are left behind to grieve:

Oh yeah, the funeral, this relates to what I was saying. She said [his mother], what do you want? If I outlive my mum, who is a strong Catholic, she does support assisted dying. If she wants a full requiem mass with communion, everything like that. I said, 'that'll be fine.' 'Why do you not want that?' After death, it is about

those who are left behind. Not the person. if that help mum get through the grief then that is fine. But, like I say, people are deprived of that. (Mark)

Florence discussed a case in Australia where a partner who had accompanied his wife for AD abroad had been arrested upon his return to Australia:

It was what she wanted. He hadn't broken the law. And he was released with... fancy a mourning man coming away from his, you know, his dead wife to face all of that, because she couldn't stay in Australia and have it done quietly just seems inhumane. (Florence)

It is possible that Florence is contemplating her own partner's return when raising this example, and her own fears about him having to face possible prosecution, even if he has not done anything illegal. This, added to the grief he will be experiencing, she finds "inhumane".

Group Experiential Theme 2: A Desire for an Honest and Open Discussion Regarding Assisted Dying

This theme arises out of participants' desires to have an honest and open discussion about AD with their family, HCPs, and the wider society. Some felt that they were not able to fully explore their own thoughts around AD because they had to keep it a secret from family and their GPs. Participants had very few outlets for exploring their own wish for AD for fear of negative responses from others or possible legal repercussions. Several participants reported the research interview was one of the few places they could explore this topic and found this beneficial. As well as participants feeling that the legal status limited their ability to discuss AD, they also felt that there was a taboo in wider society about death and dying and, as such, this taboo impacted on how others responded to them, when they raised the topic of AD.

Wanting to Be Heard

This subtheme highlights participants' desire for their thoughts and feelings around AD to be heard by HCPs, loved ones, and wider society. This desire arises out of their own needs to explore their current relationship to AD and to feel that others are willing to listen to their concerns.

Julie felt that her sense of trust with her GP was being broken by the current legal situation in the UK as she was not able to talk honestly with her GP. Julie described different aspects of self that she felt she should be able to reveal to her GP: her complete self; the nature of her illness; her body and, the many other aspects of her life. There is a sense that her previous experiences with doctors have focussed on the medical/physical aspect of her body and illness, leaving much unsaid. Although she refers to other people's needs when giving the example of speaking with a doctor in the quotation below, she is, perhaps, referring to her own wants and needs:

People need to be able to trust the doctor. They need to be able to go to the doctor and say what they feel about themselves, their illness, their body, their lives and not have someone sitting there all wimpy who does not want to talk about it. No, I don't like that [laughs to self]. (Julie)

There is a sense that the doctor's inability to engage on the topic might mean that Julie feels she has to hide aspects of herself. Perhaps doctors' silence in the past has caused her to feel shame for these hidden aspects, when in fact she may be proud, and wants to be open about her choices and the nature of her situation. She wants a doctor willing to engage in tough conversations. For Julie, trust is tied to honesty and, as such, perhaps there is a sense that she cannot trust a doctor who she is not able to be honest with. Especially if that doctor is shutting down the conversation. Sue felt that doctors leaned towards treating the visible body,

only that which is observable, but for her this can miss the patient's phenomenological experience of inhabiting their body:

And I think conversation. Yeah, I think so. Just be open to it. To be open to it and just understand where the other person is coming from. And understand, try, and maybe understand their position because doctors know all about our bodies, but they don't know what it feels like to inhabit them. (Sue)

Again, there is a sense that Sue desires to be heard and to be allowed, or invited, to have an open conversation. It is possible this stems from a desire for connection, for the bridge between the doctor and the patient to be crossed. If this bridge was crossed, perhaps it would leave Sue feeling like she could fully communicate about all the difficulties that come with inhabiting her deteriorating body. There is a sense that Sue is not expecting a doctor to fully understand her situation but feels that, for the doctor to not even try to understand it creates an imbalance in their relationship. Julie spoke of hiding her decision regarding AD from friends, she explained, "No one knows about it. They are not gonna see me any differently because they don't know what I'm going to do". Perhaps this also speaks to a loneliness that comes with having to keep her decision secret. A fear about negative responses and feeling rejected by friends was based on previous experiences of discussing her desire for AD:

Because I've sometimes talked about it to friends and had them look a little bit ensconced with me. 'Oh well, or erm'. One friend, I mentioned it to she said, 'Oh, I don't agree with that at all. I think we should just wait for God to take us' (Julie)

Mark gave talks and seminars at HCP training courses to explain his situation related to AD. It seems like it appeared to Mark that there was a disconnect between politicians, and the HCP governing bodies, and the interactions he had with HCPs that he presented to. He felt well heard and supported by students, who overwhelmingly supported his right to choose an

AD. Although Mark generally found people receptive to his talks, he did encounter some negative responses:

The only bad things I get is from the Christian groups, I've been called a fascist. Believe me, I'm anything bar a fascist. I've been called Hitler, I've been called anti-disability and I'm being accused of wanting to start polemics. The abuse is dreadful. The majority of the response of people around me is supportive, the public at large. (Mark)

Mark was able to take this in his stride, which was reflective of his self-deprecating humour and his strong belief in the importance of rational discourse, but it must still have been difficult for him to experience:

So, when I see anything derogatory, I do always try to respond to it, but in a very academic approach. I don't get in to vitriol or anything like that, and it wins people over. (Mark)

Betty echoed the sentiment of wanting to be heard by HCPs. When asked if she had any advice for HCPs she stated:

Try and spend the time, to listen... to your patient and hear properly, hear and process, you know what, what they're saying to you and their, their reasons for thinking that way. And, erm, it's always difficult to say, 'just put yourself in my shoes,' that's hard to do, it is difficult to do. You know, erm, I think, you know, most health care professionals have had some experience of seeing people suffer the end of life in whatever way. So, you know, you know, that you can always, you know, point them towards that. Ask them to think about that. (Betty)

Betty first talks about the doctor listening to patients but it seems she does not view the listening role as a passive endeavour. She hints at wanting the doctor to be truly 'hearing' her. For Betty, being heard means someone getting close to her experience of illness but also

communicating that they understand. Betty seems to believe that, if the doctor truly heard her and understood her suffering, they would understand her choice to pursue an AD, even if they personally did not agree with AD. It feels as if, perhaps, Betty has not been listened to, that HCPs have failed to communicate to her that they understand how she is feeling, and this is driving her advice for HCPs.

A few participants remarked that the research interview was a positive experience and had created an environment where they able to discuss their thoughts and feelings about AD. Sue stated the research questions, “pushed me to articulate stuff that I haven't really articulated”. For Mark, it seemed as if being heard during the interview process, of being given an opportunity to talking about his experiences related to AD, allowed him to feel alive and gave his day some extra meaning. He felt enjoyment from the conversation:

It's been a good time, I've enjoyed, I've actually lived a bit for the day. I'll go and finish this ironing now with a little bit more zest. If you or any of your colleagues want to, if you want to seek clarity on anything or want to pass my details on to any colleagues, please do. (Mark)

Debbie found benefit from the research interview but was also interested in reading the findings from the project, with a hope that her interview would contribute to the current debate, “No, no, I'm rather stimulated and curious as they say. Erm, and is there an opportunity then? Would you ever? [send her the results of the study] Because I'd be really interested to read?”.

Perception of the Topic of Death and Dying Being a Taboo in the UK

This subtheme looks at how participants make sense of HCPs', family members' and wider society's responses to the topic of AD. Several participants felt that this taboo was one of the reasons that explained why others responded to them discussing AD in the way they did. Participants also felt the illegal nature of AD in the UK was responsible for friends and

HCPs reluctance to engage with them on the topic. HCPs were often vague in their responses, leaving participants guessing as to how they really felt about them.

Sue talks about believing there is taboo in society around death and dying, and is angered by the way society, and HCPs, seem to have this compulsion to keep people alive:

It's viewed negatively [by HCPs] because we have this awful taboo about death...

Have this chronic taboo about death, this compulsion to keep living, mmm, to deny this, what should be quite a gentle natural act. We want to surround it with intubation and emergency rooms and despairing stupid attempts to keep bodies that are absolutely worn out alive. For what! The sentiment of their remaining relatives. Erm, they don't, they don't know what it's like to be in that body and for most of these people, they've had enough. (Sue)

Sue speaks to her perception about the medicalisation of death and her frustration and anger at what she sees as futile attempts to keep people living longer than they personally want to. Sue feels that this over-medicalisation is informed by wider society's taboo around death and dying. She speaks to the idea that doctor's do not understand the suffering and pain that dying people experience. There is a sense that Sue views the current approach to death and dying in the UK as being at odds with the experiences of those being treated. Perhaps this frustration arises out of a belief that the patient's wishes at end-of-life are silenced and what was once a 'gentle natural act' has become something else entirely.

Julie described feeling silenced by the illegal status in the UK. When she received the news she had been accepted by Dignitas she stated:

It's not something I can go and talk to people about. It's against the law in this country. So, I cannot go and tell people, I cannot go and discuss it with friends...

And I don't but I've been fortunate that I've trained as a counsellor. And of course, you have to be able to keep a lot to yourself, you know, when you do that, it was

okay. I was able to keep it to myself, you know? You know, in a way it would be better if I could discuss it with my loved ones and my friends and you know, do it here in this country, in my own bed! You know, and just go to sleep. (Julie)

Julie relied on her training as counsellor to be able to keep her news of Dignitas secret. This silence was driven by her fears about the legal consequences of discussing her plans with someone in the UK. Despite this, there seems to be a feeling of regret, of not being able to talk about this with her friends and loved ones, and a sense that this silence is placing a heavy burden on herself. Even though she has counselling training, this is a huge decision that she must keep quiet and bare the emotional burden herself. Also, it is not only her decision to potentially choose an assisted death that she is forced to keep secret; there will come a time when she must keep it secret that she will be leaving the country to complete an assisted death. Julie seemed to be seeking validation throughout the above quote as there is a tentativeness in what she says as she asks questions of the researcher, unsure how the researcher would respond. Perhaps this is because she is so used to keeping it a secret.

Several participants described encounters they had when discussing AD with their GPs: Some had positive experiences and others had difficulty understanding where their GPs stood on the matter. Debbie described a positive experience where she felt her GP listened and supported her without her being required to explain herself in greater detail and felt a great sense of relief at this:

Debbie: I was rather pleased, I didn't have to plead the cause, quite frankly. I think he, I think he understood what I was talking about. Erm, and maybe he felt like 'I will not be moved', but

Both: [both laugh]

Debbie: It was, it was delightfully straightforward. In the great scheme of things, and any scheme of things. It really was. So, I guess short answer, I felt relieved.

Thank heavens for that.

Researcher: Did you have a sense of how the GP viewed you as a person after that conversation, or...

Debbie: I don't think so, if he does, he disguises it magnificently. I don't see him that often... but erm, no I don't think so is the short answer.

Despite her positive experience, it seems that Debbie struggled to tell how the GP felt about her decision. This may have been due to his personality, or wanting to take a neutral stance, but could also be due to the GP's reluctance to discuss the topic further due because of fears about offering support for such a decision. Mark was similarly supported by his GP, to an extent, but still had to end the conversation prematurely, he recounted:

My GP, was restricted, I guess he supported it, but understand why he won't speak about it any further... '[Acting out the voice of his GP] I'll make sure everything's, all the bases are covered, and I'll sign it for you and put it on your record'. That was great. '[Acting out the voice of his GP] so, but what I've got to say is I can't discuss your assisted death, any further with you. What I am able to say, is that I genuinely believe that you and everybody else should have that right.

(Mark)

It is interesting that Mark decided not to follow up with his GP to clarify the GP's reluctance to discuss AD any further, again leaving much unsaid. Despite this, Mark viewed the interaction positively, which suggests that even a restricted response showing support is better than no response or a completely negative response. Julie also described a restricted response from her GP when she raised the issue of a living will and her intentions to pursue AD. Again, Julie was left to imagine what her GP truly thought:

I mentioned to him that this is what I was going to do. I was going to make a living will. Would he support me and back me up? He didn't say yes, but he nodded. Now things moved on, where suddenly got lots of chatter about the law. And, so I went back to him again. And I thought, okay, I'll just sort of see what his reaction is. And I, I just sort of said about, I said, oh, it looks like they are making a bit of a meal out of, the idea of changing the law around assisted dying in the UK. And, he didn't react. And I thought, OK, he didn't feel able to react. And I suspect that a lot of GPs are the same. (Julie)

Betty's GP also responded in a similar manner, not fully committing for, or against, support for AD:

Betty: Erm, you mean the sorts of people that are wary, yeah. I, I, I, honestly think that erm, I've touched on it with my, er, GP and I think he, he actually does understand cuz he's a decent yeah.

Interviewer: Yeah

Betty: He's a very good GP. He doesn't understand that he is frightened of openly committing himself basically.

Interviewer: Yeah. And, and how does it sort of make you feel when, when talking about these things with them?

Betty: Well, it, it does make you feel as if you're, you're talking about a bit of a taboo subject I suppose you know, because they're sort of wary, they'd rather you talked about something else a lot of the time. Yeah. (Betty)

For Betty, the doctor's response made her feel like what she was discussing was taboo and left her feeling as if he wanted her to talk about something else. For Debbie, she also viewed discussing death as being a taboo in wider society and how this taboo impacts on her and others' ability to talk about AD:

Again, I go back to my upbringing and my grandmother would talk about death. I said, 'No that wasn't a spectre at the feast, just another person at the table.' It was very much, er, hard to say, not part of the conversation. I mean, this isn't quite, as fortunately, as frequent as, that but, erm, it wasn't a great taboo and it's become a taboo, it's taken over from I know this is corny, er, sex. (Debbie)

This taboo resonated with Debbie as something she had experienced throughout her life, feeling excluded as a child from discussions of death, while not being allowed to attend funerals with the adults. She always found this taboo in wider society confusing: it was at odds with her good relationship with her grandmother, with whom she was able to discuss death freely. Debbie describes the experience of having to choose carefully who she discussed AD with, especially if she has a sense that they will not respond positively or if she does not know them very well. It seems she makes that decision about how they may respond based on what she knows about them, choosing to withhold the discussion if she feels they may respond negatively, perhaps to protect others. It is also possible that Debbie's reluctance to discuss with others is based on her own fears and worries about how others may respond, and an attempt to avoid upsetting them, rather than reflective of the actual beliefs her friends may hold about AD:

I choose my moments, erm, because I think, if I don't know someone particularly well and it's like all these things, isn't it? ...I can think of, of, of one woman in, erm, one of the book groups I belong to, who, I suspect has lived a fairly sheltered life, erm, and a comfortable monied life. And, I will suspect it hasn't perhaps run across her pen really, not something she has considered, though I don't know, erm. I tend to course, like and like. I tend not to know. And I have one, fairly Orthodox Jewish friend, with whom I would not have this conversation. (Debbie)

Betty raised the difficulty of discussing the topic of AD with her sister and how that was impacting their relationship:

Betty: No, she just, you know, she, er while, offered to you know, she's quite supportive in some practical ways, umm, [sigh] she, you know, she just she won't talk about that, she won't talk about those issues, which is a shame really.

Interviewer: And, how does that make you feel? That she won't?

Betty: Yeah, yeah, I think it's a shame because we, we could be spending better quality time together. I think we could talk about it properly, but she just doesn't want to open that one I'm afraid so. Mmm, and, you know, her religion isn't going to make me change me view [Betty chuckles]. (Betty)

For Betty, there is a wish to have a more honest conversation with her sister, and a longing for emotional support from her sister, which is not currently available to her and is affecting Betty's perception of their relationship. However, Betty seems resigned to not being able to discuss this further with her sister. Her empathy for her sister is shown with her comment that she will not convert to her sister's religious beliefs and therefore it is not fair for her to expect her sister to convert to her beliefs about AD.

Group Experiential Theme 3: Experiences of Suffering and Deteriorating Health

This theme looks at participants' wide-ranging experiences of suffering and how that relates to their declining health. It further explores how these experiences of suffering inform participants motivations and beliefs related to AD. Participants discussed the many ways that their illness had impacted their life including, affecting their quality of life, causing physical pain, and emotional distress. This suffering was described as present moment suffering but also projected forward to imagined suffering that would accompany their declining health and the difficult death that awaited them. For some participants, they knew what that

progression was going to look like, having experienced the deterioration in their parents or friends and from working with dying patients as HCPs.

Disintegration of Self

This sub-theme examines the way participants' illnesses impact their daily life and their contemplations about the likely impact of the deterioration in health that awaits them. There is a sense of grieving for the life they used to lead and the future life that they will lose as they encounter multiple and varied losses.

Betty speaks about her concerns regarding her illness from dual perspectives, that of being a former nurse working with MND patients and now as someone experiencing a slow progression of her own MND illness:

Its knowing from a nursing point of view, I am very much aware where you know, people on the street, will sort of say, 'oh but you know, you can manage end of life symptoms, you know, you can have pain relief', and that's very often the only thing they think about, they think about pain relief. They don't think about the distress of not being able to swallow your own secretions, choking on your own secretions and not being able to speak, not being able to communicate. There is, you know, there is no solution at all to a lot of these problems never mind a good solution. (Betty)

Betty spoke to the many aspects in which her health might deteriorate and how the treatment options that will be available to her will not be satisfactory. There is a sense she feels that discussions in the public, or perhaps the medical profession as well, are focussed on pain relief. For her, pain relief is only a subset of the kind of suffering a progressive illness brings. The distress of not being able to speak, of being silenced by her illness, and knowing that there is no viable treatment worries her more than physical pain that may accompany her

death. While discussing getting a new bed to help her at home, Betty describes knowing the point at which her health condition will make her life unliveable:

I'll be more comfortable. Erm, I'll, you know, erm, I'll be able to adjust me position in bed by pushing a button rather than having to move and, and those things out a little bit, but when you've worked through all that, and, and, life is becoming a miserable existence, rather than a life anymore... So personally, I think, you know, that, its, it's time to say, you know, let's end it. (Betty)

Betty realises that practical tools like her new bed will help with some aspects of her care, but she is going to reach a point where new devices and treatments will not help. When this time arrives, Betty is confident that it will be time for AD.

Mark described the loss associated with his Alzheimer's diagnosis and Sue explored the loss associated with her accident and paralysis:

[big sigh] Er... massively, catastrophically, in it, it, its life changing and it's, it's, it is like a nuclear explosion which blows apart your, your family and it also destroys your sense of identity... It destroys your biographical narrative, destroys all your assumptions that you are going to lead a long, healthy, happy life. You have to rethink everything, and erm, you have to learn to live with this awful appendage, which is your useless body. You have to learn to, to find some sort of equilibrium that makes life worth living. (Sue)

I think, now, more with the diagnosis, more than with the diagnosis, I um, sometimes I get a little bit down and I think that's more about not being able to do things... I used to work in psychology myself. I used to work around counselling, so I'm probably still going through grief process. (Mark)

The use of the metaphor of a nuclear explosion shows how huge the impact her paralysis had on Sue. The accident had impacted all areas of her life and destroyed her sense of self, her

future hopes, and dreams. Describing her body as an appendage, it seems as if Sue views her paralysed body as almost separate to her, as something that she is unable to get away from. Since the accident, Sue has had to completely change her relationship with her body, learning to live with her paralysis. Despite this nuclear explosion, Sue talks about finding an equilibrium. Engaging in a balancing act, suggestive of weighing up the good and bad that her situation has presented her with. There is a feeling that she was forced into this learning and this was not something that came easily. As discussed earlier, Sue's relationship to AD is different to the other participants, as she took comfort from being able to pursue an AD in the early days of her accident but was no longer considering an AD in the near future. For Sue, contemplating AD provided her with an escape route in case the equilibrium in her life swung too far towards suffering. For Mark, there is a sense that his loss was associated with the way his illness was impacting on his ability to do things, rather than the symptoms of the illness per se. Mark worked in academia, and this made the early stages of his illness particularly hard for him, losing his ability to read and write and having to give up his work. It was the notion of things being removed from his life that he used to enjoy that Mark found hard to cope with on an emotional level, "I um, sometimes I get a little bit down and I think that's more about not being able to do things, but then I bring my coping mechanisms into play. [pause] More fed up than depressed, I would say."

Julie echoes the sense of loss, of not being able to do the things that used to provide her with a sense of freedom:

It doesn't mean I can never do that, but I can't do what I used to do which, I mean, I could, you know, I'd enter a wood and just wander through it and take hours you know, and, er, push my way through brambles and things and trip over roots and pick myself up and, I can't do any of that now where people would say probably, 'at my age do I expect to but yes, I do' but I can't. (Julie)

Julie describes her adventurous spirit, almost carefree in her approach to walking through the woods. There is a sense of loss that runs through her statement, even with the impact of aging, she expected to be able to do more but her health issues have prevented this. These are tasks that were once important and central to her life that she is no longer able to do. It seems as if her sense of self is disintegrating over time. For Florence, when contemplating the impact dementia can have, it is her fear of having everything she holds dear, being stripped away. It is this fear of not being her old self that motivates her towards AD:

If you've got dementia, and you're not even personally family coming to visit you, but you're not that person, you're somebody else is usually not such a nice version, not that they should make the decision therefore, that you don't live but if at some point before that, you could say, I don't want to, I don't want to live with dementia, I don't want to be, you know, ready to go to a care home that's registered for dementia sufferers. (Florence)

Florence sees AD as preventing this disintegration of self by allowing her to escape before she becomes unrecognisable. A wish to avoid the illness leaving behind someone who she no longer recognises and undesirable. This is to be avoided for her, she wants to escape this possible future for herself, and AD provides her with a way out. Debbie speaks to the inevitability of her decline in health:

Debbie: And, for and to know at the same time, it's not likely to get better. Erm... so I think having this option, as, as we know, from, particularly from, um. And, erm, I think the problem about getting older, interviewer, it's a one-way street.

Both : [both chuckle]

Debbie: I ain't gonna get better. Things can only get worse. (Debbie)

With most of the participants faced with the inevitability of things not getting better, the choice of AD provided them with a way to avoid the many kinds of suffering that likely

awaited them. There is a strong sense of hopelessness in what Debbie, Mark, Julie, and Florence have discussed in this sub-theme in relation to their illnesses. They are all faced with the reality that their health is only going to get worse and they feel as if there is no hope for improvement. They know that more suffering and eventually death awaits them. It is in the context of this hopelessness that they are considering AD. It appears that AD allows them a choice, a choice to die before the aspects of their self that they cherish are lost, and it seems that considering AD is, perhaps, an antidote to this hopelessness.

Witnessing Others' Suffering in Death

It was a common experience among participants that they had witnessed a loved one, usually a parent, who had a slow, painful, death which they described as full of suffering. Witnessing the suffering their loved ones experienced informed their own beliefs about AD, leaving them hoping that they would be able to avoid the same fate.

Mark's consideration of AD began when he witnessed his father suffer with dementia. It was very painful for Mark to witness his father's decline, "I first started considering it when I was watching my dad, mmm I thought that [AD] was an, an extremely good and humane alternative". Now faced with his own Alzheimer's diagnosis, he reflected on his father's death and decided that he did not want that kind of end to his own life. He stated that he did not want others to have to remember him the way that he remembered his dying father. In Mark's mind, carrying out AD, before he got to the stage his father did, would allow those close to him to remember the good times, to remember him as he wished to be remembered:

I always said, that if I was in a similar situation, then that will be where I would go. because I think, the most important it's not a good thing for the individual, the person, to go through, and there's a second issue, it's not the kind of thing that I'd like to see people going through with me and remembering me that way rather than remembering the good times. (Mark)

It seems that this weighed heavy on Mark's own assessment of his illness and what his future with Alzheimer's looked like. He was faced with the possibility that if he did not pursue AD, he too might become the "antithesis of what he was". Knowing this, it is possible that choosing AD was Mark's way of avoiding, "an extremely bad and inhumane death" for himself and provided him an escape from imagining he would suffer the same fate as his father.

Sue also witnessed her mother die from dementia. She described how her mother had escaped from the care home one evening and laid down in the nearby garden, at night, to die. Sue felt there should have been a better alternative to her mother's end-of-life experiences in the care home, "I really like the idea of sort of wandering off into the forest". When exploring her mother's death, Sue posited:

It is what the Native Americans used to do...when they knew that their time was up, they would just wave goodbye to the tribe and tell them to keep walking and they would just sort of lie down and wait for death. And, I think there is, there is something in, that, that primitive urge is still with us. It's what animals do. It is what the tribes used to do, and I, I actually think that, there is an element that remains, a primitive element remains in us, that instinct, to not to be a burden to, to, to allow the young to thrive and move on and enjoy life and then we'll check out please. (Sue)

For Sue, the idea of a more natural death arose in response to her experiences of what she perceived as the overmedicalisation of death in the West. She feels that HCPs keep people alive longer than necessary, prolonging their death, while removing the individual's right to decide when they should die. There was perhaps a longing underlying Sue's beliefs concerning AD, a possible desire to be able reclaim death back from those she perceived to be in control. She seems to wish for a death more connected

to nature and the natural order, a death that was more reflective of an active choice rather than one that is at the mercy of medical interventions and, ultimately, to not be trapped in a care home like her mother was. For Sue, it appears that AD was her way of “wandering off into the forest”. Sue’s relationship to AD was different to other participants, as her choice was not predicated on a future decline but arose out of her feelings following an accident that left her paralysed. When confronted with the reality of having to spend the rest of her life in a wheelchair, she discussed feeling that she immediately wanted an assisted death. Knowing she had the choice of AD provided her with hope, to be able to live her life more fully. She knew she always had an option to escape her situation if she needed to, “look, there is always an option to get out of this if you don’t want to, if you don’t want to go on, but you sit there you, weep and you think, well there is a reason to get on”.

Betty talked about experiencing a friend from an MND support group have a difficult death, this “added fuel to the fire”, further supporting her belief that there should be the option available of AD:

I, think it, it, sort of added fuel to the fire if you like. I mean, it didn't exactly change my opinion. Cos, I, I pretty much knew what my opinion was before that experience. But, um, you know, it, it, sort, of supported my, the way I was already thinking, I think, yeah. (Betty)

Group Experiential Theme 4: The Importance of Autonomy and Control

This overarching theme relates to the desire for participants to have autonomy over the manner and timing of their deaths. This desire for autonomy was rooted in the belief that they should have personal freedom, a right to choose, and the right to self-govern their own decisions related to end-of-life, dying, and choosing an assisted death. Their belief in the right to choose AD can be seen as a logical extension of who they were as people and

representative of the values they held important in all other areas of their life. A desire to control the manner of their death was an action that arose out of their valuing of autonomy. Faced with uncertain futures and difficult deaths, participants wanted to feel like they had some certainty and control over their destiny. The possibility of choosing AD provided them with this perception of control. Further to this, there was a strong sense that they did not want other people to be able to exert control over their personal freedom to choose AD. They viewed the current social context in the UK as governed by people trying to prevent their right to choose AD. Tied into the idea of control were the participants' fears around becoming a burden to others, of no longer being self-reliant, and perceptions of what that burden may entail.

Valuing Autonomy and Wanting Control

The importance of autonomy was central to all the participants' world views and was often something they believed in long before they became ill. This value appears to guide their moral stance towards AD and they found it frustrating when others infringed on this. Out of autonomy arose the importance of a sense of control over their life and death:

Being in control of, of, my life, life, and my death. Being in control of that, not having someone else in control, not having someone else telling me I can't die, because we don't like it. You know, 'God wouldn't like it and we don't like it'.

You know, 'we're not going to change the law therefore and you are just going to have to suffer'. I mean, that's like a red rag to a bull. It's my life, it's my life

[angrily exclaiming] and therefore I should be able to die when I want to. (Julie)

There is an anger and indignation above that she feels towards those trying to deny her right to AD. At this point in the interview her anger and tone intensified. She referred to herself as the raging bull and those she perceives as trying to control her are waving the red flag. She feels a strong sense of ownership over her life and would likely charge down those she

perceives as holding the red rag, it feels as if she is perhaps taunting them to do so. From Julie's perspective, she is the one who must live her life, live with the consequences of her illness, and experience her own death. Therefore, it does not make sense to her that someone else should be able to be involved in her decision making. The above example highlights how important the value of autonomy is to her and how strongly she feels when others try to deny her that right.

There was a sense of an 'us or them' mentality among participants in the study. Those in support of AD who were on their side. Those against AD were seen as trying to exert control over the participants lives, which was frustrating to experience for the participants:

I think sadly, I do think it plays a role in the way, you know, politicians, the law, some doctors, regard the issue. I think religion does play a part, but it, it should be down to, you know, the patient's decision making, not the decision making of those sorts of people, it's, it's a very personal decision. (Betty)

Debbie also highlights the centrality of the ideas of autonomy and control to her decision-making regarding AD:

Oh, I should think it is hugely, important [laughing]. Yes, I mean, really important... and it's such an interesting notion I always think control. Just in terms of what that means... And I think particularly having been on my own, for a long time, being in control. Erm, yes. It is important. (Debbie)

Debbie shares that she had lived independently for a long time. Perhaps she raised this point to highlight that she is used to being in charge of her life, of not taking any input from others and this shows how she values freedom to make her own choices, with her right to AD being an extension of this.

Sue discussed the idea of taking control back from fate and destiny, with AD allowing her to be in charge of her life and death. There is a sense that perhaps for Sue, this desire to

control fate and destiny has come in response to her accident which left her paralysed. Considering AD soon after her accident provided her with a sense of control and certainty when faced with her new and uncertain reality. Perhaps she was even reclaiming her life from the potential fate and destiny that played a role in her accident. Sue described herself as feminist, comparing the right to abortion with the right to AD, and for her, the slogan, “my body my choice” applied to this debate:

It is about, it's about controlling your fate. Take control of your body and your destiny and your fate. It's just like being able to go to B&Q and choose what colour wallpaper you want or what colour you want to paint your kitchen. And it's all it is. It belongs to me. My choice. You know, you can go online, and you can choose, you know, 50, 50,000 different pairs of, of, denim jeans... But you can't choose how to die. You live in a consumer society. And a very, very fundamental basic right to choose how we end our lives, is denied to us. (Sue)

It feels as if there is a frustration and exasperation underlying what Sue is saying. In all other areas of life people are free to choose, but for Sue, with death and dying, as it is currently in the UK, that choice is taken away. For Sue, this is not just some intellectual argument, she feels it deep down inside herself. There is a sense of intuition that guides her belief in her right to have dominion over her own body. She describes it as is something more important than the laws of the country, describing it as, “a human law, it’s a law of the jungle”. For Sue, the belief in her right to choose AD is transcendent of societal values and norms. This choice relates to what it means to be truly alive, she sees herself as no different to an animal in the jungle and it is her primal right to die how she chooses. This strong belief in her right extends to a deep conviction that others should not have dominion over her body, which she describes as being the boundary of her self:

The, boundaries that the, the areas where I control in my life. I have a very strong sense of them and nobody else has the right to, to impinge on them. They're not they're not I mean, I'm not a law breaker in any other regard. I think laws are generally very fair. But when people erm, do not live in my body, whose completely different bodies are covered with different faith, different place or faith are trying to tell me what to do with my body, they are, they are breaking, something that's more, more than just the law of the country. It's, it's a, it's a sort of, erm, It's a human law, it's a law of the jungle. (Sue)

The belief in having autonomy and control also extended to the preferred kinds of death that participants hoped for. This was linked to their ideas about a good death, hoping for their ideal situation, if AD was legal in the UK. They wanted a death, on their terms, that they could control, at home, surrounded by friends and family:

I thought that is how it should be for everybody, you know, in their own bed with the family and the pets around, it shouldn't be having to go off to a clinic abroad and you know, hope that the police don't stop you. (Julie)

My ideal death would be to have people come along on the day that I have chosen to die. Those, and play some old music, have a few drinks with my friends. I have lovely cakes that people tend to appreciate and those want to stay can stay and those who want to leave can leave. Share my death with me. (Mark)

Not Wanting to Become a Burden on Others

This subtheme arises out of the participants' beliefs about not wanting to become a burden on their family and loved ones. Both in the present moment and in future situations in which they imagined that their health had deteriorated further and refers to the perception of what becoming a burden would feel like. The subtheme is reflective of a state of mind they inhabited, looking towards a time when they would feel that they were too much of a burden

on others. Becoming a burden was described by some in practical terms of the impact their illness was having on their day-to-day reliance on loved ones. For others, it was related to a sense of the emotional burden they felt their family would feel watching them slowly deteriorate, which would be followed by witnessing them experience a difficult death.

For Debbie, having AD as an option was discussed in relation to her worries about how others may suffer while observing her own suffering. Perhaps Debbie, from a place of compassion, wanted to avoid that suffering for others as much as possible, "Because it is there, it is an option. I think... anyone, anyone who, er... loves you or is fond of you can find it variously painful to see someone suffering, and in pain".

For Betty, the thought of her family having to cope with her deteriorating health due to MND kept her up at night with worry. She is aware of the likely emotional and physical burden her illness will put on her family. Betty had slowly been losing her independence at home, finding it harder to do things around the house and now using an electric wheelchair to leave home. Betty's imagined future deterioration is also based on her experience of the slow loss of independence she is currently experiencing. This is leaving her worried about how her family will cope. A sadness comes over her as she reflects on this, and on the suffering, she feels she is going to inflict on her family, "How other people are gonna to cope with that in their, in their lives. Umm [slight wavering in voice due to sadness] And then that keeps you awake at night".

Mark was aware that the progression of his dementia was beginning to make him reconsider doing things he used to enjoy, faced with the fear that his friends would soon become his carers. As discussed above, Mark witnessed his father's decline with dementia, and this was at the forefront of his decision-making regarding AD. It seems that the image of his father's decline weighed heavy on his decision making and he was clear that he wanted to avoid his friends having to experience that. However, it appears he was also aware that it was

inevitable that their relationship would change as his illness progressed. In the meantime, Mark wanted to avoid activities that would make him dependent on the help of others and one of these was no longer going to European away football matches, which is something he had enjoyed throughout his life:

One of my fears now is that friends become carers, so I think there are going to be more changes...I've been, I've been going there since 1964. I used to go to all the away games, European. I think now I'm going to have to make a choice because I don't want to become dependent. (Mark)

Florence discussed a previous health issue that had left her temporarily in a wheelchair, and discussed her difficulty with the experience of being reliant on her family for support:

I've got kids, but I really resented, not resented other people for helping me but hated that position. And I was but I was going to be well, and I was going to be over it. And I've got my life ahead of me to think that I was going to have to surrender myself to the good or bad offices of other people. For the last few months of my life is just I just dread it, I just absolutely dread it. (Florence)

As Florence projected forward to her imagined future decline, her past experience was at the forefront of her worries. However, her previous experience had been temporary and now she feared that next time it would be permanent. She hoped that she could avoid seeing their sadness and to not have to experience her own death reflected back to her through the suffering of her family:

Yes. [pensive pause] I would, I would not want to put, urm, my loved ones in the position of having to watch me die. And from a personal point of view, I wouldn't want to watch them watching me die. I wouldn't want to see my death in their eyes. And, you know, know, it was inevitable. Seeing their sorrows, seeing their

sadness, seeing whatever. I wouldn't want to see that mirroring. Um, I would, um, I wouldn't resent there being, them being there. But I would resent being in that position of utter helplessness. Yeah, I think I would resent that. I would rage against it. I would not be a nice person. (Florence)

It seems that Florence not only has to face her own dread about becoming a burden to others but she also has a desire to avoid having to watch her loved ones watch her die.

Discussion

General Summary of the Results Section

This section includes a discussion of the results and will show how the findings fit into the existing research literature, where they further the current research and where they differ. This will be followed by an exploration of the strengths and limitations of this project. The implications of the findings from this study will be discussed in relation to clinical practice, wider training, and policy, followed by the closing conclusion.

The four main themes presented in this research project help to further the understanding of the experiences individuals who are considering AD while living in the UK, where such a death is illegal. All participants valued autonomy and their belief in their right to be able to choose AD. This wish to choose the manner of their death was often tied to fear of future deterioration of their health and participants were aware of the many kinds of suffering that would likely arise. AD was seen as providing comfort, a sense of security, a way to have a good death, and allowed them choice in the manner of their death. Some participants had witnessed others go through a difficult death, which they wanted to avoid repeating for themselves. Further to this, participants did not want to feel as if they were a burden to their family. This analysis highlighted the unique experiences of participants in the UK contemplating AD abroad, which included their worries associated with illegality of such a death, their experience of AD being a taboo in the UK, and their interactions with HCPs when raising AD. Participants wanted to have an honest and open discussion about AD but felt unable to do so.

Experiences of Suffering and Deteriorating Health

A range of suffering was experienced by participants in the present study in relation to their health, which included: physical pain; inability to do things they previously enjoyed; loss of freedom; anticipatory fear; and, a loss of a sense of self. These findings are in line

with previous research into the topic of US and AD (Dees et al., 2010; 2011). Overall, participants experienced a change in their relationship with their bodies due to their deteriorating health and the impact this was having on their ability to function and engage in activities they enjoyed.

Previous research has categorised physical pain resulting from health conditions as an important motivator for choosing an AD (Dees et al., 2011; Ohnsorge et al., 2014; Pearlman 2004). However, that research was conducted in countries where AD is legal, in clinics that were providing AD to patients receiving palliative care. This may be one reason why the current research did not have such an emphasis on physical pain as a motivator for AD. The participants in this study were not considering pursuing AD in the immediate future and therefore their health conditions had not deteriorated significantly so that pain was a primary motivator. One study conducted in Canada reported that pain was not a motivator for considering AD (Nuhn et al., 2018), with pain being discussed less often as motivator than the loss of ability to engage in activities that accompanied functional decline in another (Sperling et al., 2022).

Participants in the present study reported a sense of loss, the inability to do things they used to enjoy, which was combined with the knowledge that things were only going to get worse, as their illness progressed. An inability to engage in activities was associated with a loss of a sense of who they were, a disintegration of self, a loss of their personality, which has been reported in prior research (Pearlman et al., 2005). These findings, alongside research showing HCPs proclivity to focus on pain and physical effects of illness when assessing for eligibility for AD (Pasman et al., 2009), rather than psychological motivators, show that it is important for HCPs to take a holistic approach to understanding requests for AD. The current study's findings suggest that there may be several stages to the decision-making process with regards to choosing AD. An individual's reasons for choosing AD in the early stages of their

illness may be related to anticipatory fear and worries about how their illness might progress. This fear, for some participants in the current study, was rooted in their personal experience of loved ones going through a difficult death, which supports previous research on anticipatory fear in AD (Pearlman et al., 2004).

The physical deterioration experienced by the participants, and the anticipatory fear of future physical deterioration, seemed to lead to participants' experiencing a changed relationship with their bodies, which, in turn, impacted how they viewed themselves, and the world. This changed relationship with their bodies altered their thoughts and feelings in relation to their consideration of their lives and AD. The theory of embodiment, which has its roots in the phenomenology of Merleau-Ponty (1962), states that there are two distinct ways in which an individual can experience their body: Firstly, that of the lived body, the subjective experience of inhabiting a body; and, secondly, that of the corporeal body, which is associated with the body as a distinct physical object. The theory of embodiment posits that, "a body is always perceiving and engaging with its environment while at the same time [it is] a material object within this environment" (Fernandez, 2020, p. 4405). This theory helps to understand the participants' description of their changing relationship to their bodies. In the context of the experience of the lived body, feeling as if their bodies were preventing them from living the lives they wanted to live; feeling a sense of alienation towards their bodies; and, experiencing fear about how their bodies might deteriorate in the future. In relation to the corporeal body, the participants may have experienced HCPs talking about their bodies as objects. Due to the nature of their conditions, they may also have experienced their bodies as objects, as objects that were out of their control and would require care from others or would need treatment from HCPs.

Biographical disruption refers to the experience of an individual who has had an illness which has affected their body and which then alters their embodied orientation to the

external world (Engman, 2009). For participants in the current study, things are forever changed by their illnesses and the impact on their bodies; the biographical stories they tell themselves about their lives are disrupted. The lives they had imagined for themselves are now disrupted and no longer available. They have to enter a new relationship with both the lived body and the corporeal body. This new relationship impacts how they consider their lives with illness, their possible futures, how they might experience death, and the possibility of AD.

Participants in the present study were generally in the early stages of the illness and its impact on their ability to function. They often projected forward to an imagined scenario, where their illness had deteriorated significantly, and it was this imagined decline they wanted to avoid. Again, this highlights the difference between research conducted early in the decision-making process, in a country where AD is illegal, compared to research conducted towards the end of an individual's life at a specialist AD clinic. As the illness progresses, factors related to pain, or side effects of ineffective treatment, may become more prominent. Hopelessness is often associated with depression and suicide in the research literature (Weishaar & Beck, 1992) and has been shown to be a major factor in seeking a hastened death when faced with a terminal cancer diagnosis (Breitbart et al., 2000). In cognitive research in depression in older adults (Hernandez & Overholser, 2021), this hopelessness is a result of cognitive biases and fears about the future and can be reduced by psychological therapy that helps an individual re-evaluate their interpretations of life events. However, when people are experiencing progressive illnesses, such as Alzheimer's, MND and terminal cancer, they may be realistic in their interpretation of their future decline. Their hopelessness arises out of lack of effective treatment and an awareness of the very difficult death that awaits them. Hopelessness is a key factor when individuals are considering AD (Dees et al., 2011). However, this does not mean that hope is not available in other areas of an

individual's life but, in terms of the manner of their death and dying, it did not seem that participants had any hope that things would improve. Therefore, it is likely that being able to choose an AD provided participants with hope: for a better death, and to have control over how they die. Research in terminal cancer patients has highlighted the dialectical nature of hope and hopelessness: the two are constantly in interaction with each other, often moderated by a perceived sense of control and acceptance (Sachs et al., 2013). Research in terminal cancer patients, has shown that hope is associated with better psychological and spiritual wellbeing (Chu-Hui-Lin Chi, 2007). Therefore, it is likely there are many psychological benefits for individuals from the hope that arises when contemplating an AD.

The Importance of Autonomy and Control

The concept of autonomy has been consistently shown as a key motivator in those considering an AD (Dees et al., 2011; 2013; Nuhn et al., 2018; Ohnsorge et al., 2014; Pronk et al., 2021; Van Wijngaarden et al., 2016; Young et al., 2021). All participants in this study discussed the importance of the principle of autonomy, the right to self-govern, and to have freedom to make their own choices. Being able to control the manner of their death was a high priority, especially when faced with the potential for considerable suffering associated with their illness, which they viewed as unnecessary and avoidable. These findings are in line with previous research showing that AD allows patients to take back control from the progression of their illnesses (Nuhn et al., 2018; Ohnsorge et al., 2014). It is interesting that participants talked about control being a major factor in their decision making because whether they would be successful in pursuing AD was not within their control. They were still reliant on carers, the organisations abroad, being well enough to travel, and not being stopped by the police. It seems as if control was about having a choice or at least the illusion of choice. The idea of the 'paradox of control' (Young et al., 2021) has been suggested in relation to AD: participants seeking AD want control to avoid a painful slow death that is

often prolonged by medical interventions but then request AD that is controlled by a medical system sitting within a restrictive legal framework. This paradox of control exists for patients in both countries where it is legal and illegal.

Participants discussed wanting to take back control from HCPs and be in charge of their own destiny. This notion of reclaiming dying from those who seek to control it was also reported in Richard's (2017) study on AD in Scotland, with a participant hoping to have a death in Switzerland, in a less medical setting. The roots of the concept of 'medicalisation' have been attributed to Michel Foucault (2002). Medicalisation is the idea that normal, natural, events, in society have been taken over by the medical establishment, e.g., death is viewed as an illness and the act of dying is a medical event requiring medical intervention. Conversely, de-medicalisation, is the idea of removing the medical establishments control over natural events. There have been some claims that a de-medicalised approach to AD may offer benefit and that a less medicalised discourse would be beneficial to those involved in considering AD (Ost, 2010). The concept of a natural death was highlighted by Sue, when she discussed her mother escaping from her care home to lie down in the forest and die on her own accord. Sue wanted to claim death back from the grips of the medical profession and return it to a more natural process.

The notion of control was closely tied to participants not wanting to feel as if they were becoming a burden on others. The concept of being a burden also related to the individuals' own feelings of worthlessness that can arise due to the disintegration of their self, of no longer being able to do the things they used to enjoy and is not solely based on the physical impact of burdening others (Pearlman et al., 2005). Most participants described becoming a burden in this study as a psychological state, of feeling that they are, or would become, reliant on others in the future. When they were at the stage of being fully reliant on carers, they felt they would no longer have control or freedom of choice. Interestingly, this

sense of being a burden did not seem to be caused by anything that their families had said or done, or if it had it had not been discussed in the interviews. Prior research has shown that even when people know others are willing to care for them, they still feel they are a burden (Lavery et al., 2001). In societies such as Hong Kong (Mak & Elwyn, 2003, 2005), where there is greater emphasis placed on collective support, this sense of being a burden is still present. No matter how good palliative or social care is, it is unlikely that they will allow patients to feel as if they have full autonomy and control over their life and death.

Contemplating Death, Dying, and Assisted Dying

When contemplating AD, participants reported taking comfort in knowing that they could choose AD as an alternative to the difficult and painful death waiting for them. This desire for a ‘good death’ has been shown to be a motivator in a wide range of research looking at AD, (Mak & Elwyn, 2005; Pronk et al., 2022; Sperling et al., 2022; Van Wijngaarden et al., 2016). In the current study, a good death would be afforded to participants by AD for several reasons: control over the manner and time of their death; preservation of dignity and self; respect for personal wishes related to death; and, alleviation of US. All factors that were shown in a systematic review to be important for a good death in those considering AD (Hendry et al., 2013).

It seems that when participants were contemplating AD, they used hope of a good death as an antidote to anticipatory fear about future decline. There was a sense of uncertainty attached to how their future lives might unfold. Some had witnessed similar illnesses affecting their parents, or through their work, but still participants ultimately did not have a “crystal ball” to see the future of their illness. As such, there was much uncertainty for them to tolerate and it feels that being able to consider AD provided them with some certainty in the face of this. Intolerance to uncertainty has been defined in the anxiety literature as an aversion to uncertainty and as finding uncertainty unbearable (Carleton,

2016). Interventions to help reduce intolerance to uncertainty have benefits across a wide range of psychological difficulties (Gentes, & Ruscio, 2011). Research into long-term physical health conditions has shown that individuals with higher intolerance to uncertainty are associated with poorer psychological well-being outcomes and worse quality-of-life (Gibson et al., 2023). Being able to contemplate AD may protect participants against the kinds of uncertainty that arise in those with chronic health conditions.

Sue's situation was different to others, she used the possibility of pursuing AD to allow her to cope with her new situation. There was a sense that adjustment to her disability was founded on the knowledge that she did not have to continue living if she did not want to. Her decision to continue with her life and find new meaning was a willing decision over which she felt total control, allowing her to feel in charge of her destiny. Albert Camus, in his essay *The Myth of Sisyphus* proposed, "There is but one truly serious philosophical problem, and that is suicide. Judging whether life is or is not worth living amounts to answering the fundamental question of philosophy" (Camus, 1942/2003, p.3). When somebody begins to consider AD, they are entering into a new relationship with life and death. They are deciding what makes their life meaningful and are creating a framework of belief to enable them to evaluate at what point their life is no longer worth living. Whether or not they ultimately go to Switzerland to complete an assisted death, they have entered a new psychological state, whereby contemplating AD provides them with some perceived control over their death and allows them the freedom to choose how much suffering they are willing to bare. This freedom to make choices related to their death and dying is repeated in the literature about what patients find constitutes a good death (Rietjens, 2006).

Participants were concerned about the implications of attempting to travel to Switzerland for AD, their worries included: being stopped by the police; completing the necessary paperwork; getting the right documentation from their GP; partners being arrested

when they returned to the UK alone; inability to discuss AD with friends due to legal repercussions; and not being able to have funerals in the UK. Some participants stated frustration at not being able to have a death at home, surrounded by friends and family at a time of their choosing. A death at home was preferred to having to go abroad to an unfamiliar place. Similar worries about the legal repercussions have been reported in the two studies conducted in other countries where AD is illegal (Richards, 2017; Sperling et al., 2022).

A Desire for an Honest and Open Discussion Regarding Assisted Dying

Participants all wished that they could have an honest and open discussion about AD with HCPs, family members, friends, and wished for more discussion about death in society. These sentiments are echoed in previous research that looked at what was important for patients during the assessment process for AD in countries where it is legal (Back et al., 2002; Dees et al., 2013; Oczkowski et al., 2021; Verhofstadt et al., 2022). This study has one major difference to previous research on the assessment process, namely that AD is illegal in the UK. Prosecution is a real threat for those considering AD abroad, and for those whose support them in any way. In the UK someone can face up to 14 years in prison if they are convicted for assisting in suicide. Partners of people going abroad to Dignitas have been arrested on their return, with one individual even being visited by the armed Swiss police while attending Dignitas in Switzerland, at the request of the UK police (Bird, 2022). This threat left participants feeling as if they had to hide parts of themselves from their GPs, even if their GPs responded in a helpful way. They felt it necessary to engage in a type of mind reading of what the doctor was thinking, especially if the doctor had explicitly stated that they could not discuss the topic further – a hesitation likely caused by the legal implications and risk of prosecution.

For participants there was a sense that raising AD was an opportunity for them to have their suffering heard and acknowledged, which is in line with the motivations behind

patients raising the topic with clinicians where AD is legal (Dees, 2013). Research looking at the client's perspective on whether a therapeutic relationship is effective has shown that clients create a hierarchy of needs including: client-therapist match; openness on the behalf of the therapist and client; openness allowing deeper connection; and, finally that displays of disrespect or disempowering actions prevent formation of the therapeutic relationship (Noyce & Simpson, 2018). Although Noyce and Simpson (2018) focused on psychotherapy, these factors likely play a role in all therapeutic relationships. Research has shown that an outright denial of a request for AD, or a physician's refusal to talk about it, can have negative impacts on patients' mental state (Hagens et al., 2017; Verhofstadt et al., 2022), leaving them feeling misunderstood and like their suffering is not taken seriously. However, even if physicians were unable to grant their patient's request for AD, it did not affect their therapeutic relationship, if they were able to discuss the request rather than shut down the conversation (Verhofstadt et al., 2022). Verhofstadt et al. (2022) concluded that it was important to explore AD with patients for two reasons: to see if it is a genuine wish to pursue AD and to use the opportunity for the patient to have their suffering recognised and understood. Verhofstadt et al.'s (2022) findings support the conclusion that a patient raising a request for AD is not solely driven by a wish to actively pursue AD but relates to far more complex and nuanced wishes to discuss suffering and to feel heard and supported by HCPs. These findings align with the participants in the current study who reported frustration at being unable to discuss AD but also a sense of relief when they were able to do so.

Participants in the present study took great comfort knowing that AD was an option for them, whether or not they will eventually complete an assisted death is hard to say. Longitudinal research in Holland found that most people who discuss AD with their physicians do not end up dying by AD. They found that discussions about AD were:

A dynamic emergent process that is well situated in cultural norms of overleg (deliberation). 'Euthanasia talk' has two very important consequences. First, because the interchange typically occurs in stages in which the GP pauses or stalls the trajectory of euthanasia discussions, the onus is on patients to move euthanasia talk forward. Euthanasia talk is not something that once initiated, continues towards euthanasia death without repeated effort by the patient' (Norwood et al., 2009, p. 479).

The possibility of a 'dynamic emergent process' is denied to UK patients who are not able to discuss AD with their HCPs. Discussion of AD in countries where it is legal, occurs between patients, family members and HCPs and has the function of allowing the individual to make meaning of their death and dying process (Norwood et al., 2009) and shows that a request for AD is no guarantee a patient will complete their request.

Despite an apparent hesitancy to discuss death in the UK, the largest poll to date put UK public support at 82% for changing the law related to AD (Populus, 2015). Participants in the current study felt that some of the difficulties having honest and open conversations were down to a general taboo about death in the UK. It is important to separate the illegal status of AD in the UK from the idea of there being a taboo about death, although they likely influence each other. Feeling like there is a taboo is a psychological reality. Participants in the current study had experienced negative responses from friends and family and perceived the wider medical profession to view their choice for AD negatively. As discussed in the previous theme, some participants felt that the medicalisation of death contributed to this taboo. Participants' own uncertainty and fears about how the conversation would impact others also seemed to contribute to holding back discussions.

Participants in the present study reported benefit from taking part in the interviews, describing them as one of the few places where they were able to explore their feelings

related to AD. This shows that further research on AD in the UK is likely to be beneficial to participants, researchers, and society.

Consideration of the Quality of the Study

To the best of the researchers' knowledge this study is the first to look at people living in the UK who are considering AD abroad using IPA. This methodology allowed the researcher to focus in-depth and explore the richness of participants experiences. Recruitment to the current study through AD charities and online AD groups contributed to a seemingly homogenous sample. Due to the limited pool of potential participants, all participants who contacted the researcher, and were eligible, were accepted into the study. Given limited participation from males, the results may not represent the experiences of men considering AD. However, IPA is not as interested in finding generalisable findings but aims for depth and resonance, which was achieved in this project. It is hard to say why the gender imbalance occurred in recruitment. The demographic data of those travelling to Dignitas from the UK is not available, but longitudinal studies on AD in Switzerland have shown that there is an even balance between the genders of those completing AD (Steck et al., 2016). Perhaps the imbalance in the current study was due to factors related to gender. It is possible that men are less willing to discuss AD openly in the UK and this might be rooted in wider difficulties men have about seeking medical help and discussing their psychological issues (Clement et al., 2015). However, it could also be a result of the recruitment strategy. Perhaps men are less likely to be members of the charities and support groups that were used for recruitment in this study. However, due to the lack of demographic data available on this population it is not possible to know for certain. Future research might seek to address this imbalance in recruitment and to look at how gender impacts the experiences of people considering AD.

Participants in the present study were all white British, over the age of 56, with the majority being atheist or only nominal, non-practicing, Christians. As stated above,

demographic data is not available for those attending Dignitas from the UK. Support for AD can vary across ethnic groups, with white populations more likely to support it (Braun et al., 2001). However, it has also been shown that the relationship between AD, race and ethnicity is complex, with huge variance in within-group differences as well as between-groups (Cain et al., 2018), while some research has not found a difference between ethnic groups (Periyakoil, 2016). Religious affiliation and behaviours are associated with lower support for AD (Burdette et al., 2005; Jylhänkangas, 2014), which may be the reason for the lack of religiosity in the present study,

IPA acknowledges that the interpretation arrived at in the analysis is only one possible interpretation. As described in the methodology section, much care was taken to ensure that each stage of the research project met the CASP (CASP, 2018b) qualitative checklist criteria, and that the analysis conducted met the four important criteria for qualitative research (Yardley, 2000). The reflexivity of the researcher has been described, and the research team worked on each stage of the analysis to ensure that analysis was rooted in the dataset, with the opportunity to discuss findings in relation to real world experience of working with people pursuing and completing an assisted death afforded by the second supervisor's context. Examples of each stage of the analysis have been provided in Appendix I for transparency.

Another strength of this research is that it was able to navigate a potentially difficult ethical and legal situation to deliver a safe research project. It is important that researchers continue to conduct research on hard to access populations. This population can find it difficult to talk to their HCPs and loved ones, as well as feeling silenced by the societal beliefs and the legal status. Despite this, participants found the interviews to be beneficial and hoped that their interviews would contribute to the furthering of the general conversation in the UK.

Another limitation of the current research is the potential heterogeneity of the sample in terms of the stage they were at in their AD journey. Due to the legal status of AD, it was not possible to determine how likely, or close, they were to going abroad to complete an assisted death. The experiences of someone considering AD when they are travelling the following week to Switzerland are likely to be different to someone who is thinking about some hypothetical time in the distant future. However, this is also a strength of the study, as it is not set in an AD clinic where AD is legal. Therefore, little is known about any of the potential stages of the decision-making process in the UK and these findings are an opportunity to begin uncovering these experiences.

Clinical Implications

Participants felt silenced by the current legal and societal context in which AD exists in the UK. It is important that HCPs can talk openly about death and dying with patients on a general level but it is also important that they are able to engage with individuals if they raise the topic of AD. HCPs do not have to offer their support when a patient raises the topic of AD, but to not engage in a conversation risks fracturing the therapeutic relationship and could prevent important conversations about the suffering a patient might be experiencing. In line with previous research, HCPs should be aware to not only focus on managing pain and the physical symptoms of chronic and terminal illnesses. Although these might be within the remit of HCPs to treat, or refer onwards, there are many other areas of suffering that patients can experience that need exploring in a therapeutic environment. These can include losses associated with the inability to engage in activities they used to enjoy, losing a sense of control, hopelessness, and feeling as if they are becoming a burden on others. These areas of suffering can be explored by clinicians with patients in a therapeutic environment, without HCPs providing explicit support for or against AD.

When a patient raises AD with HCPs it can have several meanings. The intent of declaring this wish should be explored by clinicians, while remaining within the current legal framework. HCPs can use these conversations as an opportunity to explore many aspects of the patient's life, with the hope that they may be able to support the patient to reduce suffering in areas that it is possible to do so.

The concepts of autonomy, freedom of choice, honest conversations, and control over treatment options are all familiar topics for clinical psychologists and other HCPs. Respecting an individual's autonomy and dignity, exploring treatment options, and respecting patient's wishes with regards to the manner and location of their deaths, is not outside of existing clinical and ethical frameworks that HCPs work (e.g., HCPC, 2023). Respecting these values and the patient's wishes are part of everyday clinical work and central to effective treatment in other areas of mental and physical health treatment.

AD is a contentious legal and ethical topic and HCPs will have their own views about the morality of AD. Whatever the clinician's personal views on AD may be, it does not change the fact that there are individuals who will be pursuing AD abroad, who need to be supported to ensure they receive the best care available to them while in the UK. A patient raising AD is an opportunity for the clinician to explore the many motivations this person may have, to look holistically at all areas of their life and to ensure that everything is being done to help alleviate any suffering they might experience.

HCPs do not avoid talking about illegal activities such as substance misuse or avoid exploring an individual's suicide ideation for fear of them acting on these thoughts (Blades et al., 2018). If clinicians are acting within the law, a patient raising AD is an opportunity for a rich and nuanced exploration of the patient's life, wishes, hopes, dreams and fears and is an opportunity for the patient to feel as if their suffering is being taken seriously. However, it is important to note that this research project is not offering legal advice. The researchers are

aware of the difficulty around the legal grey areas of discussing this issue with patients. This project has attempted to present the experiences of individual's considering AD, to allow others to better understand their perspectives, which in turn can hopefully inform clinicians as to the kinds of things that are important to these patients. The current UK law still needs to be followed.

This research has highlighted that individuals feel silenced by HCPs, wider societal debates on AD and death more generally, and by the current illegal status of AD. There is a responsibility on HCPs to be able to talk about death and dying more broadly with their patients, with AD being one aspect of this conversation. Participants did not like feeling as if control over their death is held by HCPs. These factors have implications for policy and training. It is incumbent upon the professional bodies such as HCPC, BPS, and GMC to create literature and training to support clinicians to be able to have conversations about AD in a legal, ethical, and therapeutic way. Even though governing bodies themselves are divided in their support for a change in the law, they still have a duty to provide clinicians with the tools to navigate this tricky but important clinical work. Hopefully these findings will help guide the professional bodies to think more seriously about AD and to develop training and guidelines that will benefit HCPs and their patients.

Suggestions for Further Research

People seeking AD are often supported to do so by family members or friends (Dees et al., 201). Future research should look at the perspectives and experiences of the support networks of those from the UK pursuing AD. A complementary IPA research study of family members of someone in the UK who has completed an assisted death abroad has been conducted (Hitchcock, 2023). The findings from that research study and the present one will be combined in an academic paper to further the knowledge base around the experiences of those considering AD and the impact this has on their family members. A further project with

a similar group of participants would benefit from following them longitudinally. This might help to understand how the motivations and belief in their decisions change over time and elucidate the differences between those who complete an AD and those who do not.

An additional research project looking at HCPs in the UK, whether that be in palliative care, general practitioners, or clinical psychologists, who have experienced patients raising the topic of AD, would help to understand this topic from the perspective of professionals. Due to the lack of guidelines from professional bodies, conducting focus groups with different professions around the topic of AD may be beneficial to help identify gaps in knowledge. The focus groups might help provide questions that professional bodies could answer with formal statements and professional guidelines around the topic of AD. With very few statements on the conduct of HCPs in relation to AD available in the UK much improvement is needed to ensure the best possible care.

Final Conclusion

This research explored the experiences of people living in the UK who were considering AD abroad. This research was conducted ethically and sensitively to ensure no laws were broken and participants' dignity was respected. IPA was used to carry out in-depth exploration of the participants experiences and sense making. Four major group themes were identified: experiences of suffering in relation to deteriorating health; the importance of autonomy and control; contemplating AD; and, a desire for an honest and open conversation around the topic of AD. The researchers, in line with the IPA methodology, accept that the interpretation presented is only one possible interpretation, but they note that considerable effort has been made to ensure that interpretation is rooted in the dataset. These findings have shown the important motivators and concerns that people in the UK experience when considering the illegal act of AD. The novel findings from this hard to access population will hopefully provide clinicians with insight into the decision making of those considering AD

and will allow them to explore this topic sensitively, if they encounter a patient who raises that they are considering AD.

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Appendices

Appendix A – Summary Table for Included Studies in the Systematic Literature Review

Author	Location / Legal Status	Aims	Sample	Research Design and Method	Key Findings	Limitations
Back et al., 2002	USA / Legal	To explore the interactions between clinicians and patients when a request for physician assisted suicide (PAS) is being made and to see what aspects are valued by patients and carers.	Prospective sample consisted of 12 patients and 20 family members. Retrospective interviews were conducted with 28 family members related to 23 patients. A total of 159 interviews with 60 participants.	In-depth, semi-structured interviews with both a prospective and retrospective sample of participants. Grounded Theory was used to analyse the interviews.	Patients and their family members highly valued clinicians who were willing to openly discuss PAS. They also valued clinician's expertise related to the course of illness and the dying process. Patients found it difficult to interact with clinicians who avoided talking about this. It was important that the therapeutic relationship was maintained once the topic of physician assisted suicide had been raised.	Selection bias towards participants who were very motivated to undergo PAS and therefore the results might not represent those who are more uncertain around their decision making.
Dees et al., 2011	Holland / Legal	To understand US from the perspective of patients considering AD	31 Patients who had requested AD in Holland	Semi-structured, in-depth, interviews. Grounded Theory used to analyse the interviews.	US begins with the symptoms of illness and aging. Elements from medical, psychoemotional, socioenvironmental and existential themes contribute to this suffering. Physical suffering is less	US is a criterion under law in Holland and findings may not be applicable to other jurisdictions. Patient's may be trying to meet the existing criteria of 'US' with the information they

Author	Location / Legal Status	Aims	Sample	Research Design and Method	Key Findings	Limitations
Dees et al., 2013	Holland / Legal	Looking at the decision-making process of individuals considering AD	32 patients considering AD. Both those that had been granted a request and those denied. 31 relatives and 28 treating physicians.	Individual interviews were conducted with patients, carers, and physicians. A constant comparison approach was used to analyse the interview data. Two researchers read transcribed interviews and developed codes, themes, and categories.	important than other types of suffering. Important stages of the decision-making process were delineated: discussion of views and beliefs about AD; building relationships between clinician and patient; legal requirements and how to prepare and perform EAS. Patients value the input from clinicians about these difficult decisions. This should be a shared decision-making process between patient, clinician, and carers.	provide. No researcher reflexivity discussed. Selection bias of participants towards those in favour of AD. Researchers were unsure how people who are not favourable towards AD felt.

Author	Location / Legal Status	Aims	Sample	Research Design and Method	Key Findings	Limitations
Ekkel et al., 2022	Holland/ Legal	Exploring the perspectives and attitudes of people with Huntingdon's Disease who had an AED in place or were intending to draw one up.	Nine patients with Huntingdon's Disease who were recruited from four Dutch specialist nursing homes for people with Huntingdon's Disease.	Longitudinal in-depth interviews conducted over a period of 6 -18 months. Each patient was analysed longitudinally, as case studies. This was followed by a cross-sectional analysis conducted of all the interviews.	Two themes were extracted that described the participants attitudes and views towards advanced euthanasia directives: the general character of their request and the uncertainty around their request.	Only one of the participants in this study reached a stage of their illness that met the threshold for their AED. This selection of patients at nursing homes with Huntingdon's disease may not be representative of other people with this illness.
Hagens et al., 2017	Holland / Legal	To understand the routes that people take when they seek de-medicalised assistance in suicide.	17 people who had been recruited through the Foundation De Einder, a Dutch organisation that provides counselling around de-medicalised assistance in suicide.	In-depth, semi-structured interviews. The transcribed interviews were analysed with open, inductive, coding, and prior theory or framework was used in the analysis.	There were two main routes towards people considering de-medicalised assistance in suicide: Firstly, those who were currently suffering but not eligible for PAS or felt unable to access it through their current healthcare; secondly, people who were anticipating a situation with future suffering. Participants often valued	Participants were only included in the study if they were receiving counselling from the Foundation de Einder. Those who died after receiving this counselling are also missing from this study, the results might not be generalisable to all those considering de-medicalised assistance in suicide.

Author	Location / Legal Status	Aims	Sample	Research Design and Method	Key Findings	Limitations
Hagens et al., 2019	Holland / Legal	Exploring the experiences of counselees at a de-medicalised assistance in Suicide clinic in Holland.	17 individuals who had requested AD and had been referred to counselling by the AD clinic.	In-depth interviews with each participant that were transcribed and then analysed using grounded theory.	<p>autonomy over ending their life.</p> <p>Counselees gained information about their lethal medication and other ways to end their life. Counselees felt listened to and felt respected and were appreciative of a space to discuss their concerns regarding AD. Having the lethal medication did not mean that patients will use it and it can provide reassurance and increase their quality of life.</p>	Participants were recruited through their counsellors and thus may only reflect positive experiences. Study is missing those who die shortly after receiving their medication, which may select for a certain kind of person considering an assisted death. There were concerns that counselees may act in a socially acceptable way to obtain information from the counsellor.
Lavery et al., 2001	Canada / Legal	Understanding the motivations of people considering AD.	32 patients with HIV or AIDS who were enrolled at the Ontario HIV database.	In-depth exploratory interviews around participants decision making related to AD. Grounded theory was used to develop a model from the data.	The desire for AD arose from the idea of the individual's sense of self disintegrating due to their illness. There was a loss of community that was brought about from isolation due to inability to engage in activities that	Difficulty accessing patients due to the illegality of AD in Canada at the time of the study, which prevented theoretical sampling strategies.

Author	Location / Legal Status	Aims	Sample	Research Design and Method	Key Findings	Limitations
Leboul et al., 2022	France / Illegal	To explore the purpose of a patient's request for AD in a country where AD is illegal.	18 patients interviewed within 48 hours of a request for AD being made.	In-depth, semi-structured, interviews conducted with patients, family members and physicians. Data analysed using a hermeneutic phenomenological approach.	were previously rewarding. Impairment of functioning further contributed to this sense of a loss of self. AD was seen as a way of stopping this disintegration of self. Five motivations for requesting AD clarified: transgressing the forbidden; a desire for US to be understood; a wish to alter clinical practice gaining a sense of freedom from their medical illnesses; and, the wish for a desirable future.	Patients' health limited the length and depth of the interviews being conducted. Reliant on clinicians passing on the patients' request for AD to the research team.
Mak & Elwyn, 2003	Hong Kong / Illegal	To see the effectiveness of using phenomenological hermeneutic research in patients considering euthanasia.	Six terminally ill participants in a palliative care Hospice in Hong Kong	In depth, semi-structured, qualitative interviews analysed using a phenomenological and hermeneutic approach.	Hermeneutic research is effective in a palliative care setting and the interviews were tolerable to participants. The dying trajectory worse than death itself, the anticipation of death as difficult, the desire for a good death, intolerable suffering and a sense of burden were reported.	Findings potentially limited to the social and cultural context within which they were conducted. The dual role of the researcher as a clinician may have led to some bias. However, reflexivity discussed at length in this paper.

Author	Location / Legal Status	Aims	Sample	Research Design and Method	Key Findings	Limitations
Mak & Elwyn, 2005	Hong Kong /Illegal	To develop an understanding of the meaning of desire for requesting euthanasia.	Six terminally ill participants in a palliative care hospice in Hong Kong who had requested euthanasia from their primary physician.	In depth, semi-structured, interviews with the interview structure and analysis guided by a phenomenological approach that wanted to get close to the subjective meaning of the participants experiences.	Five major themes related to participants desire for euthanasia were identified: reality of the disease progression; perception of suffering for self and significant others; anticipation of a future worse than death itself; desire for good quality end-of-life care and, the holding environment provided by healthcare professionals and loved ones.	Findings potentially limited to the social and cultural context within which they were conducted. The dual role of the researcher as a clinician may have led to some bias. However, reflexivity discussed at length in this paper and research team involved at all levels of coding and analysis.
Nuhn et al., 2018	Canada / Legal	Understanding the reasons why people consider MAID.	11 participants who had requested and were eligible for MAID in Canada with various chronic or terminal illnesses.	In-depth, semi-structured, interviews analysed using thematic analysis.	Reasons for considering MAID included: loss of autonomy; loss of control of their body; an inability to communicate and, a fear of future suffering. Pain was not stated as a factor that made them consider MAID.	The participants were recruited from a single clinic in Canada and may not be reflective of the rest of the country. Selection bias may mean that people who choose not to discuss this topic have different views and are not represented in the findings.
Oczkowski et al., 2021	Canada /Legal	To explore the experiences of people related to	21 patients and 17 family members who had been	In-depth, semi-structured, interviews were conducted and then	Provided several themes to guide clinicians in how to meet patients' needs related	Lack of participants from rural and remote communities. No

Author	Location / Legal Status	Aims	Sample	Research Design and Method	Key Findings	Limitations
		their use of an existing MAID clinic. Looking at both the process of the clinic and quality of care.	accepted for MAID across four Canadian centers. Participants had a wide range of chronic illnesses, with cancer being the most common.	analysed using a qualitative descriptive approach.	to their MAID requests, MAID assessments, and supporting the patient with their preparations for dying. Patients regarded choice related to death and aftercare as important to the process and valued the therapeutic relationship with clinicians.	demographic data on race and ethnicity provided and unable to account for the different clinics' ways of working and how that might have impacted on patients' experiences.
Ohnsorge et al., 2014	Switzerland/ Legal	To understand the motivations of terminally ill patients who have expressed a wish to die.	30 patients with advanced cancer disease, their family members, and carers at a palliative care service in Switzerland.	In-depth, semi-structured, interviews analysed using IPA	The motivations of a wish to die can be separated into reasons, meanings, and functions. The meaning to the patient of a wish to die is as important as their stated reasons or causal factors. Social and spiritual were the main reasons suggested.	Further research needs to examine the impact of cultural and contextual factors on the meanings of patients' declarations a wish to die. Reflexivity of researchers not discussed.
Pasman et al., 2009	Holland / Legal	To gather information on the views of patients and physicians when a request for euthanasia has been denied.	10 patients who had explicitly requested euthanasia, but the request was not granted. 8 physicians whose patients had died before the request	In-depth, semi-structured, interviews analysed used open coding and qualitative analysis.	Patients who request euthanasia emphasise the psychosocial suffering whereas clinicians emphasise the physical suffering. Patients do not always conceptualise their suffering as unbearable.	Only looked at cases where a request for euthanasia had been denied and that may reflect more disagreement between clinicians and patients.

Author	Location / Legal Status	Aims	Sample	Research Design and Method	Key Findings	Limitations
Pearlman et al., 2005	USA / Legal	To collect extensive narrative data on the motivations of individual's considering PAS	could be granted or had died after their request was denied. 60 participants who had requested PAS. 35 participants in total, 23 family members of historical cases where they had completed PAS, and 12 current patients who were considering it.	In-depth, semi-structured, interviews, analysed using content analysis method.	The impact of the progression of the illness, the loss of the sense of self and fears about the future were the three main factors identified. Pain is less of a factor than physical functioning and a loss of ability to engage in meaningful activities.	Reflexivity of researchers not discussed. Participants were a self-selecting group of recruited through support organisations. The views discussed may not be representative of the wider population. Reflexivity of researchers not discussed.
Pronk et al., 2021	Holland / Legal	To understand the reasons why patients with mental illness may request and explore the possibility of AD	21 patients who had requested AD due to suffering from their mental illnesses.	In-depth, semi-structured, interviews analysed using thematic analysis	Autonomy and self-determination, bringing an end to their suffering and tiredness from fighting their mental illness were major factors in their request. The request was an attempt to be seen and heard by clinicians. AD was more considered than suicidality, which participants felt was more impulsive.	Respondents may have been disproportionately dissatisfied with the Dutch mental health care system. Participants were at varying stages of their journey in relation to AD which may influence their perspective. Limited discussion of researcher reflexivity.
Richards, N., 2017	UK / Legal	To explore why individuals consider	7 people based in the UK who were	In-depth, semi-structured, interviews, as	Participants were attempting to leave their	Due to the limited participants, it was hard to

Author	Location / Legal Status	Aims	Sample	Research Design and Method	Key Findings	Limitations
Sperling, 2022	Israel / Illegal	To understand the experiences of Israeli nationals who were members of Dignitas and considering AD.	11 adults from Israel considering AD aged between 35-81 with various illnesses, functional disability, and experiences of social isolation.	In-depth, semi-structured, interviews, with questions in the interview being partly determined by responses from participants. The data was analysed using Grounded Theory Approach	The lack of ability to function as they once could was more important to participants than the nature of their illness, as a determining factor when considering AD. Participants did not generally feel sad about their situation. Poor experiences of the healthcare system and the inability to discuss their wishes with medical professionals was an issue. The importance of being able to choose when they	state that thematic saturation had been reached and the sample is of convenience rather than representative. There was not much discussion of how the analysis was undertaken. Limited discussion of researcher reflexivity. A small sample size but this was determined by the limitations of studying a hard to access population in a country where AD is illegal.

Author	Location / Legal Status	Aims	Sample	Research Design and Method	Key Findings	Limitations
Van Wijngaarden et al., 2016	Holland / Legal	Case study of a couple who were planning to engage in spousal self-euthanasia in Holland.	An elderly couple who jointly wanted to choose to die together, at a self-directed moment, as they felt life was completed and no longer worth living.	In-depth, semi-structured interviews. The husband and wife were interviewed separately and then interviewed together. Analysed using a thematic existential phenomenological method.	die and issues with the legislation were reported. The couple reported an alienation from their body and identity and a feeling of emptiness in their life. Their decision to undertake an AD was based around anticipatory fear of deterioration of their physical health and losing control around the manner and time of their death in the future. There was some disagreement between the couple about when the right time to act on their wish might be.	Case study may not be reflective of other couples in this situation. Ethical concerns around the impact of the research and whether the researchers needed to address a potential power imbalance between the couple around certainty of AD. However, participants were competent, consenting adults who did not feel that this imbalance needed addressing.
Verhofstadt et al., 2017	Holland / Legal	To investigate the experiences of suffering in patients who had made a request for euthanasia	The testimonials of 26 psychiatric patients who had attended psychiatric out-patient setting in Belgium.	Analysis of written testimonial, and one video, that were spontaneously submitted by patients discussing their reasons for requesting euthanasia. These had been placed in the medical records of the patients and were	Five areas of US were extracted from the testimonials medical; intrapersonal; interpersonal; societal and existential. Psychiatric issues are not the only source of suffering for these patients but physical and psychosomatic symptoms too. US	As the testimonials were spontaneously submitted, they were reliant on the communication of the patients and may not have provided as much depth or nuance as an in-depth semi-structured, interview. These testimonials were

Author	Location / Legal Status	Aims	Sample	Research Design and Method	Key Findings	Limitations
Verhofstadt et al., 2022	Holland / Legal	Exploring the impact of the euthanasia assessment procedure in adults with psychiatric conditions	16 participants in Belgium who had made a euthanasia request between 2016-2020. Including participants who had had their request for euthanasia, accepted, neglected, denied, or put under review.	then anonymised and analysed using QualiCoder software, using coding and thematic analysis. In-depth, semi- structured, interviews looking at the motivations for euthanasia and the impact of the assessment procedure. The qualitative data was analysed using open, inductive, data-driven thematic analysis	experiences are also affected by socioenvironmental, existential, biographical factors with hopelessness a factor too. Participants reported a benefit of feeling that they were listened to as part of the assessment procedure and that their requests had been taken seriously. Participants reported that the euthanasia assessment procedure may suppress suicidality and provide a space for them to consider alternative to death. However, most participants struggled with ambivalence towards the decision regardless of whether their request was granted or denied. The importance of how the request was denied by clinicians was raised and	submitted to the physicians deciding their euthanasia request so certain elements may have been exaggerated to ensure they met the legal criteria. There is a potential lack of thematic saturation for the final themes discussed in this paper. The participants were recruited by physicians who were conducting these assessments, and this was done at a time where the law was changing around the requirements of the assessment, which may reduce the applicability to other patients undergoing this assessment.

Author	Location / Legal Status	Aims	Sample	Research Design and Method	Key Findings	Limitations
Verhofstadt et al., 2021	Holland / Legal	To understand why psychiatric patients request euthanasia and how this relates to suicide.	16 participants in Belgium who had made a euthanasia request between 2016-2020. Including participants who had had their request for euthanasia, accepted, neglected, denied, or put under review.	In-depth, semi- structured, interviews looking at the motivations for euthanasia and the impact of the assessment procedure on patients. The qualitative data was analysed using open, inductive, data-driven thematic analysis	the impact this denial had on people considering AD. Patients reported being in emotionally worn-out states, because of an accumulation of difficulties in their lives which lead them to feel that their lives were no longer worth living. They viewed euthanasia as being a good death over suicide which may produce complications. Patients often experienced a long history of adverse events and stated that they were suffering from complex lives, rather than a mental illness. Some patients longed for death to be reunited with their partners. Patients felt that improved mental health care would help to reduce their requests for euthanasia. Patients also felt that stigma and poor youth services contributed	Study was conducted at a time when there was much public scrutiny and media attention on a patient with a psychiatric illness considering euthanasia, which resulted in a change to the law and guidelines in the country and this may have affected patients' responses.

Author	Location / Legal Status	Aims	Sample	Research Design and Method	Key Findings	Limitations
Young et al., 2021	New Zealand / Illegal	To explore the concept of individual agency, and control, when related to AD in New Zealand with participants who would consider an assisted death if it was legal.	14 participants who were approaching the end of their life and had life limiting illnesses such as, advanced cancers; motor neuron disease' and, rare autoimmune disease were interviewed. Six of the interviews also included a family member.	In-depth, semi-structured, interviews took place. The interviews were then transcribed and analysed using thematic analysis and immersion/crystallization from a Foucauldian perspective.	to their current state of suffering. Every participant stated that they thought dying should be within their control and this helped to reduce anticipatory suffering. The ideas of personal freedom and autonomy were also related to this, with AD felt to be a human right. They felt this was important even though their control would be limited by the state and regulations.	Participants were asked directly about control and its importance, rather than having more open-ended questions to explore the possibility of this idea.

Appendix B - Evaluation of Qualitative Research Papers for Review using the Critical Appraisal Skills Programme (CASP)

Author	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Back et al., 2002	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Dees et al., 2011	Yes	Yes	Yes	Yes	Yes	No. Not discussed in method section.	Yes	Yes	Yes	Valuable
Dees et al., 2013	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Ekkel et al., 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Hagens et al., 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Hagens et al., 2019	Yes	Yes	Yes	Yes	Yes	Yes. Discussion of interviewer's previous experience	Yes	Yes	Yes	Valuable

Author	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
						and experience as a psychologist discussed within the research team.				
Lavery et al., 2001	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Leboul, 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Mak et al., 2003	Yes	Yes	Yes	Yes	Yes	Yes, reflexivity discussed at length.	Yes	Yes	Yes	Valuable
Nuhn et al., 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Oczkowski et al., 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Ohnsorge et al., 2014	Yes	Yes	Yes	Yes	Yes	No. Reflexivity not discussed in the methods section, but coding was	Yes	Yes	Yes	Valuable

Author	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
						done by multiple team members.				
Pasman et al., 2009	Yes	Yes	Yes	Yes	Yes	No. Relationship between participants and researcher not discussed.	Yes	Yes	Yes	Valuable
Pearlman et al., 2005	Yes	Yes	Yes	Yes	Yes	Researchers were expert clinicians in the area but the relationship between participants not discussed in method section	Yes	Yes	Yes	Valuable
Pronk et al., 2022	Yes	Yes	Yes	Yes	Yes	Partially, some mention of the limitation of only having one person conduct the interviews and	Yes.	Yes.	Yes	Valuable

Author	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
						develop initial codes. Although discussion of how all researchers worked on developing the themes from the initial code to overcome this issue.				
Richards, N., 2017	Yes	Yes	Yes	Yes	Yes	Partially, impact of the legal status on the researcher/participant relationship discussed.	Yes	Yes	Yes	Valuable
Sperling, 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Van Wijngaard	Yes	Yes	Yes	Yes	Yes	Yes	Partially. This study did address	Further discussion of the	Yes	Valuable

Author	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
en et al., 2016							the ethical issues raised with interviewing on such a sensitive topic and discussed the implications of not intervening with the couple. This is a complex issue that could have been addressed in further detail.	limitation s of this study is needed, as this is not fully addressed in the paper.		

Author	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Verhofstad et al., 2017	Yes	Yes	Yes	Yes	Yes	Yes	Partially. Analysis of historical data so relationship between researcher and participant not discussed in detail.	Yes. Although unclear how consent was gained for data to be used. Ethical approval granted by Ethics Committee, so it is assumed this was addressed.	Yes	Valuable

Appendix C – University of Hertfordshire Ethical Approval**HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA
ETHICS APPROVAL NOTIFICATION**

TO Harry Dean
CC Dr Barbara Mason
FROM Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair
DATE 24/01/2020

Protocol number: LMS/PGT/UH/04015
Title of study: Understanding the experiences of people who are considering ending their life by assisted dying

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

no additional workers named

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 24/01/2020

To: 01/07/2020

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.

Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit form EC2.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix D – University of Hertfordshire Ethical Approval Extension**HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA****ETHICS APPROVAL NOTIFICATION**

TO Harry Dean
CC Dr Jenifer Heath
FROM Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair
DATE 26/09/2022

Protocol number: aLMS/PGT/UH/04015(2)
Title of study: Understanding the experiences of people who are considering ending their life by assisted dying

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Barbara Mason

Modification: Detailed in EC2

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Original protocol: Any conditions relating to the original protocol approval remain and must be complied with.

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 26/09/2022

To: 01/02/2023

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.

Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit a further EC2 request.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A or as detailed in the EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix E - EC 6 Participant Information Sheet

Title of Study:

Understanding the experiences of people who are considering ending their lives by assisted dying.

**There are many different terms used to describe an assisted death in the literature and wider media e.g. physician-assisted suicide; euthanasia; accompanied dying etc. For the purposes of this study the term 'assisted dying'(AD) is used to encompass both physician-assisted suicide and euthanasia as outlined by Harris, Richard & Khanna (2006) and NHS Choices (2016).*

What am I reading?

Before you decide whether you would like to take part in the study it is important that you understand why this research is being conducted and what will be asked of you if you do decide to take part.

Please take your time to read the information below carefully. It aims to answer any questions that you may have about the research. However, if you have any further questions or if you are unclear about any information in these pages, please feel free to contact the researcher - details are given at the end of this document.

What is the study about?

This study aims to explore the personal experiences of those who are considering a decision to end their lives by assisted dying and what factors have led them to this decision. The project also sets out to understand your experiences of discussing assisted dying with healthcare professionals.

What do I have to do?

The main part of your involvement will be an interview, which will last between an hour to an hour and a half, where we discuss various aspects of your experiences and decision making around assisted dying. The audio from this interview will be recorded and will then be analysed by myself and the research team. Prior to this interview you will need to provide written consent to take part in the research (please see attached consent form). Once you have completed the consent form, I will contact you for a brief telephone conversation where I explain the interview and discuss your feelings around taking part in the research and we can then arrange the interview.

What kinds of questions might I be asked?

The kinds of questions you might be asked in the interview would be similar to these:

- Please tell me how your illness impacts on your life?
- Please tell me about your experiences of considering a decision to end your life by assisted dying?
- How has the legal situation around assisted dying affected your decision?
- What have been your experiences of healthcare professionals when you have discussed assisted dying with them?

The interview can involve multiple breaks as needed and can be completed across more than one meeting if doing so would be beneficial. If your illness impacts on your ability to communicate, you are welcome to bring a trusted person to support you to talk in the interview. If this is the case, please let me know and we can arrange this. They will also have to sign a consent form and agree to keep the contents of the interview confidential.

What are the benefits of taking part?

The findings from this study will help healthcare professionals to better understand the experiences of those who are considering a choice to end their life by assisted dying. The research will also help contribute to the current debate surrounding assisted dying in the UK. We hope the study will give you an opportunity for your voice to be heard and to have a space to reflect on this decision-making process.

What are the possible disadvantages of taking part?

The face-to-face interview can last between an hour, and an hour and a half. This may present you with physical demands such as tiredness or discomfort. The researcher will endeavour to make taking part as comfortable as possible. The interview can be arranged at a location of your convenience, and we can take breaks to accommodate any needs you may have. Due to the nature of this topic, some of the things we talk about may be upsetting. The researcher will support you through the interview. You are also free to withdraw from the research process at any point, without any consequences and, without having to give a reason. If you require further support following the interview the researcher can signpost you to various organizations that support people in similar situations to you.

Who will know if I take part?

Only the research team at the University of Hertfordshire will be aware of your participation. If you agree to take part in the study, you will be assigned an anonymous participant identification number to ensure anonymity. Once you have completed the interview the audio will be transcribed. When the audio is transcribed, all identifying feature, e.g., names, age, locations will be removed from the transcript. All data will be fully anonymised and anyone reading the final research will not be able to identify you or anyone that you talk about from reading the research.

What will happen to my data?

The audio from the interview will be recorded on to a Dictaphone. All data will be anonymised during the transcription process. Once the audio has been transcribed, the audio will be deleted from the device. All data such as contact details, consent forms, and transcriptions will be stored on an encrypted device at the University of Hertfordshire. Any paper documents will be stored in locked storage at the University of Hertfordshire, where only the research team will have access. All the material associated with this research project will be stored securely for up to five years at the University of Hertfordshire. Once five years has passed, the data will be deleted. After you have completed the interview, there will be a two-week period during which you can remove your data from the research. After the two weeks has passed, I will remove any link between your name and the data to ensure your anonymity. After I have removed your details, I will no longer be able to identify your data and as such, will not be able to remove it.

If the researcher has any concerns about your safety or that of someone else following the interviews, the researcher will have a duty of care to break the confidentiality of the interview. If there is an immediate severe risk the researcher may have to contact the relevant authorities such as the police or emergency services. Due to the legal status of assisted dying within the UK the interview will not discuss anything to do with your plans to leave the country or the act of assisted dying itself. This research is only interested in your experiences related to the decision-making process and not the act itself. The researcher will remain impartial regarding the legality of assisted dying within the UK.

What will happen to the results of the study?

Once the study is completed the researcher will write up the findings as an academic doctoral thesis as part of their training on the Doctorate in Clinical Psychology at The University of Hertfordshire. Following this, the study will be written up for publication in a research journal and may also be presented at an academic conference. In all documents, papers, or presentations all participant data will be completely anonymised.

What if I want to hear about the findings of this study?

If you want to know the outcomes of the study, I can forward you a summary of the findings. You can either let me know at the interview or contact me on the details below.

What if I have any questions or concerns about this project?

If you have any questions or concerns about any aspect of this study, you can speak to myself and I will do my best to respond to any questions. You may also contact my academic supervisor:

Dr Barbara Mason

Senior Clinical Tutor

Doctorate in Clinical Psychology Training Course University of Hertfordshire

Hatfield, Herts. AL10 9AB.

Tel: 01707286322

Email: b.l.mason@herts.ac.uk

This research has been reviewed by The University of Hertfordshire, Health, Science, Engineering & Technology Committee with Delegated Authority (protocol number: LMS/PGT/UH/04015).

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar

University of Hertfordshire

College Lane

Hatfield

Herts

AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

What should I do now?

If you are interested in taking part in the study, please complete the form below (See EC3) to indicate you have read this information sheet and give your consent to take part in the study.

If you are not interested in participating any further, you do not need to do anything. Thank you for your time in reading this information and considering the study.

Contact Details

Main researcher:

Harry Dean

Trainee Clinical Psychologist

University of Hertfordshire

Email: hd17aat@herts.ac.uk

Appendix F - Participant Consent Forms***Understanding The Experiences of People Who Are Considering Ending Their Lives By Assisted Dying.***

UH Protocol Number : LMS/PGT/UH/04015

I, the undersigned [*please give your name here, in BLOCK CAPITALS*]

.....

...

of [*please give contact detail here, e.g., email address or telephone number*]

.....

Please tick

1 I confirm that I have been given a Participant Information Sheet giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed and asked to renew my consent to participate in it.

2 I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.

3 In giving my consent to participate in this study, I understand that voice recording will take place and I have been informed of how this recording will be used.

4 I have been given information about the risks of my suffering harm or adverse effects. I have been told about the aftercare and support that will be offered to me in the event of this happening. In signing this consent form I accept that medical attention might be sought for me, should circumstances require this.

5 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

6 The interview will be confidential in nature. However, I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk this confidentiality may need to be broken and relevant authorities informed

8 If you need someone to assist you with communication please tick this box to show that you consent to another person, of your choosing, joining us in the interview.

Signature of participant.....Date.....

Signature of (principal)

investigator.....Date.....

...

Principal Investigator : Harry Dean, University of Hertfordshire.

EC3 II

Understanding The Experiences Of People Who Are Considering Ending Their Lives By Assisted Dying.

Translator Consent Form

UH Protocol Number : LMS/PGT/UH/04015

I, the undersigned [*please give your name here, in BLOCK CAPITALS*]

.....

...

of [*please give contact detail here, e.g. email address or telephone number*]

.....

Please tick

1 I confirm that I have been given a Participant Information Sheet giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up

studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.

2 I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.

3 In giving my consent to participate in this study, I understand that voice recording will take place and I have been informed of how this recording will be used.

4 I have been given information about the risks of my suffering harm or adverse effects. I have been told about the aftercare and support that will be offered to me in the event of this happening. In signing this consent form I accept that medical attention might be sought for me, should circumstances require this.

5 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

6 The interview will be confidential in nature. However, I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances

that would or has put others at risk this confidentiality may need to be broken and relevant authorities informed

8 I agree to keep the contents of this interview confidential and to ensure that I accurately represent the communication of the participant being interviewed.

Signature of participant.....Date.....

Signature of (principal)

investigator.....Date.....

Principal Investigator : Harry Dean, University of Hertfordshire

Appendix G - Participant Debrief Sheet

Understanding The Experiences Of People Who Are Considering Ending Their Lives By Assisted Dying.

Participant Debriefing Information Sheet

UH Protocol Number : LMS/PGT/UH/04015

Thank you very much for making this study possible.

Through this study I am aiming to explore how considering assisted dying impacts on a person's life. I am interested in the processes of considering this decision along with how this impacts on people's lives. Through the study, I also hope to explore the impact of the current legal position within the UK as well as people's experiences of their interactions with health and care professionals when discussing this issue. This study is also interested in the decision-making process and the impact this process has on someone's life.

There is currently a lack of research literature within the UK surrounding this topic. As such, your involvement will help to further the knowledge base within this area and will help provide clinicians with information on how best to support people in the future who are in a similar situation to yourself.

Sources of comfort and help

Talking about your experiences may have left you feeling low or upset. This is quite normal and should pass within a few days. However, if these feelings persist there are local sources of support and comfort, which may already be familiar to you.

1. The most immediate sources of comfort and help are likely to be your own family, friends, and carers.

2. There also are many national organisations that can be a helpful resource for support and information:

- Hospice UK 020 7520 8200 www.hospiceuk.org
- Macmillan Cancer Support 0808 808 00 00 www.macmillan.org.uk
- Marie Curie 0800 090 2309 www.mariecurie.org.uk
- MIND 0300 123 3393 <https://www.mind.org.uk/>
- Motor Neurone Disease Association 01604 250505 www.mndassociation.org
- MND Scotland 0141 332 3903 www.mndscotland.org.uk
- Progressive Supranuclear Palsy Association 0300 0110 122
www.pspassociation.org.uk
- The Samaritans (tel. 08457 909090; www.samaritans.org). The Samaritans is a helpline which is open 24 hours a day for anyone in need. It is staffed by trained volunteers who will listen sympathetically.

3. Compassion in Dying are an organisation that supports individuals with decision making related to end-of-life care. 0800 999 2434 www.compassionindying.org.uk

3. If you feel that things have become too much or you need some professional help then please contact your GP to arrange an appointment to discuss how you are feeling. If you feel that you are seriously worried that you might hurt yourself then you can always go to A&E in an emergency and they will be able to support, you.

4. You are welcome to contact me again to discuss any aspect of your participation in this study, to share any concerns you might have or to ask questions.

Harry Dean

hd17aat@herts.ac.uk

01707 286322

Doctorate in Clinical Psychology Training Course University of Hertfordshire

Hatfield, Herts. AL10 9AB.

5. If you have further concerns that you would like to raise with the University of Hertfordshire, you can contact my Academic Supervisor:

Dr Barbara Mason

Senior Clinical Tutor

01707286322

b.l.mason@herts.ac.uk

Doctorate in Clinical Psychology Training Course University of Hertfordshire

Hatfield, Herts. AL10 9AB.

Thank you again for taking part

Appendix H - Interview Schedule

Intro and setting the context

- *Introductions* –
 - Check with the participant that written consent has been provided. Ask for verbal consent for today’s interview to proceed. Ask for verbal consent for the interview to be recorded. If a trusted person is present, check that written consent has been provided by the participant and the trusted person. Ask for verbal consent for the trusted person to be recorded.
 - Explain the participant’s right to terminate the interview and withdraw from the research at any point. Explain that they can request a break at any time during the interview. State that they can pause the interview at any point and return to the interview at a later time if they wish.
- *Confidentiality* – Researcher to say “Today’s interview will be confidential. The only time I will need to break that confidentiality is if there is significant risk to you or others.”
- “We will not be talking today about any plans you may have made related to assisted dying but will be reflecting on your experiences of considering this decision.”
- *Demographics* – “Please can you tell me your age, gender, ethnicity, religion?”
- “What is your understanding of the term assisted dying? Is this the phrase you would like me to use in this interview? If not, what phrase would you prefer to use?”

Part A – Impact of their illness on their life and considering assisted dying

- It would be helpful for me to understand something about your illness; can you tell me about your diagnosis? When were you diagnosed?
- Can you briefly tell me about your illness and how it impacts on your life?
 - *Prompts*
 - Physical pain?
 - Mental health / emotionally?
 - How does it impact those around you, family/loved ones, etc.?
- Please can you tell me about what influenced you to consider a decision to end your life by assisted dying?
 - *Prompts*
 - What experiences have influenced you in making this decision?
 - Has suffering played a role in this?
 - How has the law impacted on this?
 - Has your faith/religion played a role in this decision?
- How did you feel when you first began to consider assisted dying?

- *Prompts*
 - Emotionally / physically / mentally?
 - How have you tried to make sense of this decision?
- Has coming to this decision changed your relationship to life, death and/or your illness?
 - *Prompts*
 - If so, how has it changed and in what way? How is your thinking different now to say, five years ago?
- What is important to you about being able to consider ending your life by assisted dying?
 - *Prompts*
 - *Having control? Having some certainty? Having a choice?*

Part B - Impact of the legal status in the UK

Has the current legal status of assisted dying impacted on you and your decision-making process?

- *Prompts*
 - If so, how?
 - How you view your illness?
 - Has the legal status influenced how others view you?
 - What would a change in the legal status mean to you?

Part C Your experiences of health care professionals when discussing these issues

- Have you discussed the topic of assisted dying with the healthcare professionals you have seen?
 - *Prompts*
 - If so, how did their response make you feel?
 - How do you think they viewed you as a person?
 - How did you view them after your conversation?
- Do you have any advice for healthcare professional's when they work with someone considering assisted dying?

Ending

- We are reaching the end of the interview now but is there anything that you would like to have talked about that we did not get to?
- How did you find the interview today?

Provide debrief sheet. Offer check-in next week. Explain what will happen with the project and ask if they want to receive feedback from the findings of the project in the future.

Experiential Statements	Sue- Transcription	Initial comments Plain Text – Descriptive <u>Underlined</u> – <i>linguistic</i> <i>Italic</i> – <i>conceptual</i>
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	08:41 [REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	08:58 [REDACTED]	[REDACTED]
[REDACTED]	09:09 [REDACTED]	[REDACTED]
[REDACTED]	09:12 [REDACTED]	[REDACTED]

Experiential Statements	Sue- Transcription	Initial comments Plain Text – Descriptive <u>Underlined</u> – <u>linguistic</u> <i>Italic</i> – <i>conceptual</i>
<p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p>	<p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED] 11:36</p> <p>[REDACTED] 11:37</p> <p>[REDACTED] 11:43</p> <p>[REDACTED] 11:44</p>	<p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p>

Experiential Statements	Sue- Transcription	Initial comments Plain Text – Descriptive <u>Underlined</u> – linguistic <i>Italic</i> – conceptual
<p>[REDACTED]</p>	<p>[REDACTED]</p> <p>12:12</p> <p>[REDACTED]</p>	<p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p>

Appendix Ib – Stage Two Complete list of Sue’s experiential statements

Complete List of Experiential Statements		
[REDACTED]	[REDACTED]	[REDACTED]

Complete List of Experiential Statements

[REDACTED]	[REDACTED]	[REDACTED]
------------	------------	------------

Appendix Ic – Stage Two - Sue’s Clustered Experiential Themes

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]



Appendix Id – Stage Three - Sue’s Table of Personal Experiential Statements

[REDACTED]		
[REDACTED]		
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]

[REDACTED]		
[REDACTED]		
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]		
[REDACTED]		

[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]

[REDACTED]

[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]		
[REDACTED]		
[REDACTED]		
[REDACTED]		
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]		
[REDACTED]		

[REDACTED]	[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]	[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

