How does assisted dying affect the experience of the bereaved in the UK?

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere

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Abstract

Background

Assisted suicide is a choice to die voluntarily using self-administered drugs obtained from a clinician in a country with a permissive legal framework. This study is the first to explore the experiences of caregivers bereaved by assisted suicide in the UK.

Aim

To explore the experiences of caregivers who supported a patient through assisted suicide.

Methods

A constructivist grounded theory methodology was used to analyse the experiences of British people bereaved through assisted suicide. These experiences are discussed with results of a critical interpretative synthesis review of studies on the experience of people bereaved through suicide, to further develop a grounded theory of the experience of those bereaved by assisted suicide.

Findings

Thirteen interviews were conducted with 13 caregivers of 9 individuals who died due to an assisted suicide. Participants sought to honour the wishes of the person seeking an assisted suicide. The role included responsibility to plan the death, engage in gatekeeping information about the planned death from those who might not agree and usually accompanying them to their death. Fear of legal sanction and social stigma led to secrecy associated with an experience of isolation and after the death, some engage in campaigning to change the law.

A critical interpretive synthesis of the experience of those bereaved by suicide shows similarity with the experience of those bereaved by assisted suicide in that they share the experience of stigma and isolation and have the capacity to campaign to challenge this stigma of suicide.

A grounded theory is presented that links the experience of enabling an assisted suicide with subsequent campaigning, allowing the bereaved to challenge the stigma and make meaning of their experience, including the opportunity to justify their role to enable the death.

The dual process model (Stroebe & Schut, 2010) supports improved understanding of the needs of those bereaved by assisted suicide, both before the death (including opportunities for anticipatory grief), and as part of bereavement, illustrating the dynamic processes that require both loss orientation and restoration orientation activity. The study presents the first application of the dual process model to anticipatory grief.

Conclusion

Those bereaved by assisted suicide in the UK believe that this was the best available death for their relative or friend, despite the anxiety and distress they experienced. Since the death they campaign for legalisation of assisted suicide in the UK to challenge the stigma they experience, to be more open and less isolated, and understand their experience. They receive little support before, during and after the death and the dual process model can assist in understanding how best to support those within the UK and elsewhere, with the complex and challenging experience of being bereaved by assisted suicide.

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Chapter 1. Introduction

1.1. Research Question

How does assisted dying affect the experience of the bereaved in the UK?

A grounded theory study from a constructivist approach (Charmaz, 2014) gave insight to the experience and needs of those bereaved in the UK, by assisted suicide. A qualitative study allows exploration of this population whose experience has been little recorded, and how this might differ from other bereavement experience. Semi-structured interviews collect data from UK residents who have been bereaved by assisted suicide which occurred in other countries with a permissive legal framework.

1.2. Motivation for research

As a psychotherapist and counselling service manager, supporting bereaved clients in community, hospital, and hospice-based bereavement services I am aware of how the experience of bereavement is significantly affected by the circumstances of the death. I have approached this research to learn more about the needs of this group of bereaved people in the knowledge that although this is currently a relatively small number of people in the UK, the number of people bereaved in this way across the world is growing as legislation is passed to support assisted suicide.

I have found that the needs of families and the bereaved are often minimised, giving priority to the needs of the dying person however it is important to consider these people as the impact of caring for someone choosing assisted suicide may be considerable. As a manager and clinical supervisor of bereavement care services, developing the standards of services for the bereaved, it is important to understand how the experiences of those bereaved by assisted suicide may be similar or different to the experiences of those bereaved by suicide and what special consideration and care this group might need.

1.3. Positionality

Whilst my professional experience has been in the role of psychotherapist with a psychological focus on the experience of individuals in both my training and within my practice, I have become increasingly aware of the social influence upon how the bereaved experience their grief. I acknowledge the social construction of grief, and this informs my approach to understanding how best to develop and offer support to the bereaved, for example in understanding that individual bereavement counselling may be less helpful than social support from self-help groups. This view of the social construction of grief also helps me to consider the different cultural, social, and legal factors that influence the individual experience of the death of someone significant in our lives.

As my counselling experience has been focused on the care of the bereaved within a hospital and hospice-based services, I also acknowledge the influence of palliative care approaches, having worked with multi-professional teams to alleviate the suffering caused at the end of life for patients and their families.

As a researcher I take the position that my own views and prior experience will shape the construction of this thesis and have chosen a methodological approach that offers a space to be reflexive about how I designed the research, conducted, and analysed the findings, and discuss the research.

1.4. Key Terms and definitions

A wide selection of recent and relevant publications and research will be explored within the background chapter and the choice of terms used in this thesis are listed in the table below. No choice of terminology can be completely neutral when the subject matter is as sensitive and contentious as assisted dying and suicide. My position is discussed and acknowledged throughout. In the discussion chapter I continue to discuss the construction of the meanings of assisted dying, assisted suicide and suicide and consider how this affects the experience of the bereaved.

Table 1. Key Terms and definitions

TERM	DEFINITION
ADVANCE CARE PLANNING	“Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care. For many people, this process may include choosing and preparing another trusted person or persons to

	make medical decisions in the event the person can no longer make his or her own decisions" (Sudore et al., 2017, p 823).
ADVANCE DIRECTIVE	An advance directive is a statement that can be given orally or recorded in writing, made by a person with decision-making capacity stating their wishes about how to be treated or not treated at a stage when they lose that capacity (Salins et al., 2018).
ANTICIPATORY GRIEF	"The grief experienced by family members before the death of a loved one from advanced illness. It can also be used to describe how someone with a limited life might anticipate and grieve their own death" (Strada, 2013 p.8).
ASSISTED DEATH	Assisted death is when someone makes the means of death available but does not act as the direct agent of death (Gerson et al., 2019).
ASSISTED SUICIDE	When someone makes the means of death available this can be called assisted suicide, for example, in Switzerland, [when] "people can be granted access to assisted suicide on condition that the person whose wish is to die performs the fatal act" (Gaignard, 2019, p.1.)
BEREAVEMENT	"The state of having experienced the death of someone close" (Strada, 2013 p.7).
COMPLICATED GRIEF	"Prolonged and severe morbidity caused by grief that is not effectively processed and integrated by an individual after the death of someone close. As a result, the griever is symbolically "stuck" in the grieving process and continues to experience distressing symptoms that cause severe and disabling impairment long after the loss has occurred". (Strada, 2013, p.8.)
DESIRE TO DIE	This is a reactive phenomenon affecting patients with advanced disease, an operational definition of the wish to hasten death, and regarded as a specific manifestation of the desire to die. (EAPC, 2021)
DISENFRANCHISED GRIEF	"Losses that are not supported or sanctioned by society (for example, the death of a married lover), that are not typically recognized as losses (for example, death of a pet, spontaneous miscarriages), or losses that carry significant stigma (loss of a loved one by suicide, or lethal injection for a prisoner)". (Strada, 2013, p7).
END-OF-LIFE CARE	An approach to caring for a terminally ill patient that focuses on symptom control, comfort, dignity, quality of life, and quality of dying rather than treatments aimed at prolonging life (Salins et al., 2018).
EUTHANASIA	"A medical professional administers a lethal dose of medication to intentionally end a patient's life" (Gerson, et al. 2019 p.2).

	Euthanasia can be classified as: **voluntary euthanasia** – where a person makes a conscious decision to die and asks for help to do so **non-voluntary euthanasia** – where a person is unable to give their consent (for example, because they are in a coma) and another person takes the decision on their behalf, perhaps because the ill person previously expressed a wish for their life to be ended in such circumstances (NHS, 2021).
GRIEF	"Grief is the normal reaction to loss, characterised by physical, cognitive, psychological and spiritual manifestations" (Strada, 2013 p.7).
HASTENED DEATH	Someone who acts on their desire to control the circumstances of their death with or without assistance from another individual (Gerson, et al, 2019).
MOURNING	The internal process of grieving and outward manifestation of grief to adapt to a death. (Strada, 2013).
LIFE-LIMITING CONDITION OR ILLNESS	Terms used to describe an incurable condition that will shorten a person's life, although they may continue to live active lives for many years. This might include a wide range of life-limiting illnesses that are no longer responding to treatment intended to cure (NHS, 2021).
PALLIATIVE CARE	"Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness or serious health-related suffering. It includes, but is not limited to, end-of-life care. It is not the "last resort" but should be integrated early in the care of people affected by a life-threatening condition." (World Health Organisation, 2002).
PHYSICIAN-ASSISTED SUICIDE or MEDICAL AID IN DYING (MaID)	"A medical provider writes a prescription for a lethal dose of a drug to be self-administered by a competent, terminally ill patient. (Gerson et al. 2019). The physician provides the knowledge and means necessary, but the act is completed by the patient. From the physician's standpoint, it is a deliberate act with the express intention of ending life and should not be ethically distinguished from euthanasia" (IAHPC, 2013 p.17).
SUICIDE	Self-caused death (Gerson, et al., 2019).
SUICIDE SURVIVOR	The experience of being bereaved by a suicide (Peters et al., 2016 (b)).

TERMINAL ILLNESS	A progressive condition, both malignant and non-malignant, has no cure and is expected to cause the death of a person within the foreseeable future. (Salins et al., 2018).
VOLUNTARY STOPPING OF EATING AND DRINKING	The voluntary stopping of eating and drinking by a person who wishes to hasten their death. (Lowers et al., 2021).
THE WISH TO HASTEN DEATH	"A reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death. This wish may be expressed spontaneously or after being asked about it, but it must be distinguished from the acceptance of impending death or from a wish to die naturally, although preferably soon. This wish may arise in response to one or more factors, including physical symptoms (either present or foreseen), psychological distress (e.g. depression, hopelessness, fears, etc.), existential suffering (e.g. loss of meaning in life), or social aspects (e.g. feeling that one is a burden)" (EAPC, 2021).

The right to die, to have a physician-assisted death or suicide (PAD or PAS), medical aid in dying (MaID) or euthanasia, are some of the many terms used across the world to describe when someone seeks to end their life, usually as a response to a life-limiting or severely disabling illness. Physician-assisted suicide describes the provision of the means of death to the person who wishes to die by a physician, who then carries out this procedure to take their own life (Gerson et al, 2019).

Of the participants within this study, all but one of the deceased died in Switzerland where the legal description of this kind of death is assisted suicide, as the means of death is not supplied by a physician but by volunteers working with voluntary organisations (Life Circle, 2022; Dignitas, 2022). One participant experienced the death of a relative travelling to Belgium where the designated term is physician-assisted suicide (Gerson et al, 2019).

There is currently no formally recognised legal term for this kind of death within the UK, although the legal enquiries made in the UK about these deaths are part of the law that exists relating to suicide (Suicide Act UK Gov, 1961). However, the UK Crown Prosecution Service (2022) uses the term assisted suicide in legal guidance given to those travelling abroad to die. In this thesis, I will use the term assisted suicide (AS) as this is the term used by the organisations that arrange all the deaths occurring for the participants in this research except for the death occurring in Belgium.

1.5. The organisation of the thesis

Both the organisation of the thesis and the timing of the literature review reflect the methodological approach derived from a constructivist grounded theory approach.

Chapter 1: Introduction. In the current chapter I briefly describe the factors affecting the experience of those bereaved by AS in the UK, and the thesis structure.

Chapter 2: Background. I provide a background to the current social and legal position of AS and euthanasia across the world with an overview of the situation in the UK. I then provide an overview of the research and knowledge about grief and bereavement that might usefully illuminate the experience of those bereaved by AS in the UK. The chapter concludes with an overview of the deficits in the care and support offered to these bereaved.

Chapter 3: Methodology. Examines the methodological and philosophical underpinnings for this thesis and gives consideration and justification of the constructivist grounded theory approach including an account of the reflexivity required for this approach.

In Chapter 4: Methods. In this chapter, I outline the procedures and explanation for the research undertaken as part of this thesis, including recruitment, data collection, analysis methods including use of Atlas ti.

Chapter 5: Findings. In this chapter, using constructivist grounded theory, I present findings about the experience of those bereaved by AS and present the grounded theory of enabling and campaigning.

Chapter 6: Literature Review. I use a critical interpretative synthesis of literature to explore the experience of bereavement following suicide.

Chapter 7: Discussion. In the final chapter, I offer broader discussion of the findings and grounded theory with further comparison of the literature review with the findings. I consider the grounded theory of enabling and campaigning using the dual process model and apply this to anticipatory grief occurring for those enabling an AS.

Chapter 8: The Conclusion of the thesis discusses the significance of the research, including implications for clinical practice and recommendation for future research.

Chapter 2. Background

2.1. Introduction

In this chapter I present a brief overview of the legal and social factors surrounding assisted dying across the world and the arrangements that exist to achieve this in other countries with a permissive legal framework. I will describe the current arrangements for AS in the UK, where assisting a suicide is illegal, and outline the views of some of the key stakeholders in the UK. I will review what is known about the experience of bereavement from assisted suicide and discuss this in relation to models and theories of grief and bereavement.

There is limited research on the experience or possible effect on the family members of those who choose to end their lives with assistance in the countries that now have a legal framework to support this process (Gamondi et al., 2019b). There is no research about the experience of bereaved family members from the UK whose family or friends choose to end their lives by AS, going to a country which allows this. The issues that might be important for UK citizens have not been investigated and literature that has been collected in the few studies about the effect of assisted death on bereavement have been limited and reach divergent conclusions (Fish, 2017; Gamondi et al., 2019b; Gamondi et al., 2019c).

2.2. Assisted dying across the world

In the past twenty years, over 200 million people in eleven countries have been given access to an assisted death (Mroz, 2020). Five of the countries are in Europe (Belgium, Luxembourg, The Netherlands, Portugal and Switzerland), four countries in North America (in ten US states, Canada & Quebec and Colombia), three Australian territories and, following recent legalisation, New Zealand (Mroz, 2020). Review of the laws concerning assisted dying are becoming more frequent across the world with Germany recently decriminalising assisted dying services and Spain considering new legislation. Switzerland was the first country to legalise assisted dying in 1942, followed by Belgium, Colombia and Oregon in the US, in 1997. In five further jurisdictions legalisation took place between 2000 and 2010 and then in thirteen more jurisdictions between 2010 and 2020 (Roehr, 2021) and most recently in Jersey (Iacobucci, 2021). There exists a growing body of research and writing about physician-assisted suicide (PAS), euthanasia and hastened death and health (Dierickx and Cohen, 2019) as well as exploration of how social care professionals can best offer this option to people with challenging health conditions or disabilities who seek a hastened death (EAPC, 2021).

There is a complex and varied terminology used to describe assisted dying, along with a wide variety of legislative arrangements across the world, contributing to the potential for misunderstanding (Gerson et al., 2020). The debates across the world, have been notable for their polarised campaigns taking either a ‘pro’ or ‘anti’ stance to any legalisation of physician assisted death, suicide or euthanasia in the UK (Inbadas et al., 2020) or in other parts of the world (Box, 2021).

2.3. Assisted death and suicide in the UK

2.3.1 Legal System

Whilst suicide has been legal for over fifty years (Suicide Act, 1961), assisting a suicide within the UK is currently illegal. Guidance from the UK National Health Service (NHS, 2020) states that assisted suicide ‘is illegal under the terms of the Suicide Act (1961) and punishable by up to 14 years' imprisonment’. The guidance also asserts that ‘euthanasia is regarded as either manslaughter or murder’ (NHS, 2020).

The last full debate in the UK of an Assisted Dying Bill, was unsuccessful but a second reading of a further Assisted Dying Bill in the House of Lords (House of Lords, UK Parliament, 2021a), as of March 2022 is in Committee stage when a detailed examination and discussion of amendments will take place before moving forward with any legislation. In Jersey, a UK Crown dependency with constitutional rights of self-government and judicial independence, the State Assembly backed a proposition supporting assisted dying in November 2021, planning full debate and legislation by the end of 2022 (Iacobucci, 2021). The Scottish parliament has consulted on a proposal for assisted dying for adults with a terminal illness (Scottish Parliament, 2021a) with parliamentary debate expected in 2022, and the situation in the UK is likely to be influenced by any changes.

In almost half of officially reported cases in Belgium, between 1990 and 2015, pain was given on the death certificate, as the most significant reason for euthanasia (Emanuel, et al 2016). However, pain is not the main motivation for requesting euthanasia and PAS in the United States with ‘loss of dignity’ mentioned as a reason for 84%, with 61% of cases in the Netherlands and 52% in Belgium. The use of the term dignity appears in other documents relating to assisted deaths, for example in Oregon the legislation for assisted suicide is called 'The Oregon Death with Dignity Act' (Oregon State Legislature, 1994). In the UK one of the most influential pro assisted dying, campaigning organisation with the UK is called Dignity in Dying (Dignity in Dying, 2021b).

Sarah Wooton, Chief Executive of a UK campaigning organisation, Dignity in Dying, declared that "momentum for change is building right across the UK and Ireland, and Jersey is now leading the charge. An Assisted Dying Bill is also progressing through the House of Lords, a public consultation is under way in Scotland, and a special committee on this issue will launch in Ireland in the New Year" (Dignity in Dying, 2021).

Whilst AS remains illegal in the UK, those wishing to end their lives by AS instead go abroad to countries such as Switzerland where there is a legal framework that includes those travelling from another country. The last available data from Dignitas clinic in Switzerland records that between 1998-2012, 215 people from the UK travelled to the clinic including 33 people in 2012. (Dignitas, 2014). The numbers currently travelling abroad for an assisted suicide are difficult to confirm, however the UK Crown Prosecution Service (CPS, 2021) states that between 1 April 2009 and 31 January 2021, there have been 167 cases that have been recorded as AS following referral to the CPS by the police. Of these 110 'were not proceeded with by the CPS' and 32 were withdrawn by the police. The website posting continues by stating that there are "currently eight ongoing cases and that three cases of encouraging or AS have been successfully prosecuted. One of these was charged and acquitted after trial in May 2015 and eight were referred onwards for prosecution for homicide or other serious crime" (CPS, 2021). There is no data on the subsequent success of these prosecutions and insufficient data to clarify which deaths might have been AS that have taken place in another country or might have been pursued in the UK. It is also possible that the numbers known by the CPS and reported by the police do not fully represent the numbers who travel abroad to die in this way.

It is challenging to confirm the exact number of those choosing suicide as a response to having a life-limiting or terminal illness. In response to a parliamentary question (UK Parliament, 2021b), the National Statistician Sir Ian Diamond responded that in 2019, of 5,691 suicides, 56 mentioned cancer, 264 a neurological disease, 168 respiratory disease and 321 heart disease, however, with the proviso that, “We are unable at present to collect data or provide figures specifically on suicide where the person had been diagnosed with a terminal illness, since information on the deceased’s circumstances prior to death, such as diagnosis or treatment, is not among the particulars generally recorded on the death certificate.”

Legal guidance is given in the UK by the Crown Prosecution Service (CPS) to police about how the legal system might respond to relatives of the person who has taken or wishes to take their own life living in the UK (CPS, 2014). Members of their family and friends who may have prior knowledge of the choice of an AS abroad, may to varying degrees support the choice, help arrange the death and travel there with the person when they go to die, but by doing so might be considered as assisting a suicide, illegal in the UK (UK Suicide Act, 1961).

The CPS guidance addresses some of the more frequent legal issues that arise for both the person choosing an assisted death in a country with a legal framework to offer this, and for their friends or relatives that might know about or assist them in this. This detailed guidance involves a public policy test and discusses how there must be sufficient evidence to prosecute if the case reaches the evidential stage arrangement (CPS, 2014), however without clear legislation there can be considerable anxiety for any family members of friends who might know about or assist the suicide. Recent guidance advised that those arranging AS during lockdown would be allowed to travel to Switzerland (BBC, 2021) giving further confirmation of the official recognition of this issue.

2.3.2. The bereaved and AS

An influential and potentially problematic factor acting upon the experience of those bereaved by AS may be the ambiguous legal position of those assisting a suicide in the UK. Dignity in Dying (2021), the campaigning organisation, describe how those assisting a suicide can face up to fourteen years in prison, quoting Norman Lamb. M.P.

“The current law . . . puts families in the most invidious position . . . if someone acts out of absolute compassion, they are still left with their home being declared a crime scene and with a police investigation . . . That is surely an intolerable position.” (Dignity in Dying, 2021).

The ambiguous legal situation may leave family members or those involved in arranging AS unclear about prosecution or social judgement by friends, family, health care professionals or other social groups. These bereaved people may be likely to limit those they speak to before and after the death limiting the possibilities for social support. Richards (2017, p.350) found that for many of her participants, people who were researching how to end their own lives with an assisted suicide, kept their plans secret “from family members for fear of causing them distress, of them intervening to prevent their departure; or a fear of criminally implicating them”.

Consideration of the needs of those assisting a suicide may extend to understanding that the legal situation is anxiety-provoking, however further consideration of any other complexity or issues that might arise from having someone close to you choosing to end their lives in this way is rare. For example, both UK Bills (House of Lords, 2021b) have focused primarily on ethical responsibilities and rights and to the needs of the person making this decision to end their life, with no specific reference to the experience, needs of or rights of the family.

In 2008, Dignity in Dying created a Charter for End-of-Life Care which included a call for bereaved people to have access to financial, legal, and counselling assistance and that health and social care professionals be trained with end-of-life care skills including “communication skills and high-quality bereavement skills” (Dignity in Dying, 2021a). Since then, this organisation does not appear to have developed any further plans or services that look at these issues for these bereaved other than to offer those bereaved opportunities to campaign to support a change to legalise assisted dying. Their sister charity Compassion in Dying, aims to support people at the end of life to have what they consider to be a good death by providing information and support around their rights and choices. A search of the website database of resources for bereavement or grief, shows no specific reference to research for the bereaved (Dignity in Dying, 2021a).

With limited attention given to the needs of the bereaved, both organisations are primarily concerned with the needs of the person wishing to end their lives and are not able to provide any independent research or evidence base to explore the needs of those bereaved by AS. Liz Forbat, (2018) a family therapist points out that “assisted dying is a systemic issue, with impacts on the individual, their family, clinicians and communities” (Forbat, 2018, p.478) and is concerned that the legal and ethical debates are not fully informed by consideration of the impact on the family. This thesis considers how AS affects the experience of family and close friends and will use different perspectives about what influences the experience of bereavement (Section 2.6).

2.4. The experience of those bereaved by AS in countries with a legal framework

There is a large and well-established body of research about the effect on families of suicide (not due to an assisted death) that points to many risk issues for those bereaved, finding that there is likely to be a higher incidence of distress and prolonged or complicated grief, (Wimpenny et al., 2008). This will be explored more fully in section 2.5.

A systematic review (Gamondi et al., 2019b) explored the experience of family members bereaved by assisted dying, identifying nineteen articles representing fourteen studies derived from four countries; Canada, the Netherlands, Switzerland and the three US states (Oregon, Washington and Vermont). Following coding, the review identified five analytic themes across the studies which included precursors and the context of the decision for PAS; coming to and enacting the decision; cognitive and emotional work for family members; experiencing the final farewell and grief and bereavement.

A comparison of end-of-life and hastened death caregiving experience (Lowers, et al. 2020) found that the expectation of impending death and the shorter duration of caregiving may result in less caregiver burden for those whose relatives have a hastened death. The narrative synthesis of qualitative studies began by reviewing the experiences of caregivers for patients at end of life, using this as a preliminary synthesis before asking about experiences of caregivers of patients selecting hastened death and in what ways are their experiences may differ.

Gamondi et al., (2019b) highlights how the enactment and experience of the assisted death event, and subsequent emotional affect and cognitive processes mark out this kind of bereavement as having common themes that are important and useful to understand. The authors find that family members are involved in the complex decision making and the clinical consultations prior to an AS. Gamondi, et al. (2019b) recommends that further research be conducted to build further understanding of family needs and supportive interventions to address their needs alongside the care for the patient.

Gamondi et al., (2015) also confirms the key role for families in facilitating patients in obtaining the death they wish for and notes how rarely families are mentioned or considered within the clinical guidelines in countries that have a legal framework. Also noted is the lack of consideration of their needs or the impact of their role in this kind of death. The relational and social context of how an assisted death takes place is further discussed by Buchbinder (2018) who uses ethnographic research in Vermont, US to explore how the arrangements for the death need "distinctive forms of sociality and dependency [that] require terminally ill people and caregivers to embrace a collaborative stance towards choreographing death" (Buchbinder, 2018, p481).

The experience of social isolation has been noted for families supporting those choosing AS living in Switzerland, a country with a legal framework to support physician assisted suicide (Gamondi, 2013). Despite the clearer Swiss legal framework, families felt unable to speak to some health care professionals about this issue before their relative died as they "perceived that some health care professionals had difficulty in dealing with their own personal beliefs sufficiently well, to enable an open discussion" (Gamondi, 2013 p1643). The authors suggest this view may explain the barriers in communication and suggest that families' experiences of not being able to share with others may continue after the death, contributing to social isolation.

Not all members of the family may have been included in the decision-making with the person who has chosen an assisted death (Gamondi et al 2015) which may also lead to distress for some of these bereaved. A study of the needs of bereaved families in Canada following recent legislation of Medical Aid in Dying (MAiD), (Trouton, 2020) found that physicians offering MAiD recognised that care for these bereaved was limited and patchy and needed further development. Further research in Canada, (Beuthin et al., 2021) identified the time leading up to the assisted death as critical for families, and also recommended the development of services supporting families. Research looking at decision-making at end-of-life states that families can disagree about what has taken place and come under emotional and psychological stress (Fox and Fruhauf, 2019).

Ganzini (2009) found that when comparing family members of those who had requested medical aid in dying (MAiD), with a similar group of those bereaved by death occurring due to illness, there were 'no differences in primary mental health outcomes of depression, grief, or mental health services use' (Ganzini et al., 2009, p.807). In this small quantitative study of 95 family members of those choosing an assisted death in Oregon (Ganzini et al, 2009), grief was measured using the Inventory of Complicated Grief-Revised (Prigerson & Jacobs 2009). The inventory uses questions such as 'I have regrets about how s/he died' and ‘I was at peace with the choices s/he made at the end of life' (Ganzini et al, 2009, p.813) and compared with the control group of families dying of similar illnesses. Ganzini concludes that 'families in which aid in dying was requested, felt, on average more prepared for the death, felt more accepting of the loved one's death.' (Ganzini et al, 2009, p.813).

2.5. Suicide bereavement and risk

Whilst the research offering evidence about the experience of those bereaved by AS or euthanasia is at an earlier stage (Gamondi, 2015) there is considerable evidence to suggest that those bereaved by suicide are more at risk of serious mental health outcomes including a complicated grief reaction or their own suicide (Jordan, 2001). Complicated grief is a term used to describe symptoms of grief that predict long-term functional impairments (Mitchell et al., 2004) and has been measured using the Inventory of Complicated Grief (ICG) (Maciejewski et al., 2007). Qin et al (2002) found that, irrespective of psychiatric illness and taking account of other factors such as economic deprivation, a family history of suicide increased the suicide risk for close family members.

A systematic review of qualitative research about the experience of suicide bereavement (Shields et al., 2017) looked at eleven studies that included a range of kinship relationships, including parents. The review found that feelings, meaning-making and social context were key factors affecting the experience of suicide bereavement. Feelings common to many bereaved by suicide included guilt and shame and meaning-making was complex due to lack of information and perceived social stigma.

Jordan (2020) discusses how distinguishing features of suicide bereavement can be described as the ‘perceived intentionality’ of the person choosing to die and the related ‘perceived responsibility’ for the death (Jordan, 2020 , P.1: 766). The intentionality refers to the belief that most suicide bereaved have, that the deceased chose to end their life of their own volition, and this then leads to complex issues for the bereaved such as 'Why would they choose to do this? How could they have overcome their fear of death, their responsibilities, and their love for others to engage in this behaviour?' Responsibility for the death then lies with the deceased although is usually also often initially felt by the bereaved as self-blame, and sometimes the fault of others who might have been expected to take better care of the person and thus avoided their suicide (Jordan, 2020, p. 2:766,). The literature review within this thesis uses a critical interpretive stance and will inform how the needs of those bereaved by AS might be similar or different to that experienced by those bereaved by suicide.

2.6. Concepts and theories of grief that inform understanding of bereavement

Concepts and theories of grief and bereavement can provide guidance and focus to bereavement support and care, and the research that supports them, and will be explored here to inform my understanding of the bereaved participants within this study. Using a constructed grounded theory methodology also gives me the opportunity to explore how theory influences their research activity by giving importance to reflexivity, seen as a basis to the development of constructed grounded theory (Charmaz, 2014) and this will be explored in the discussion chapter.

The following models of grief offer insight into individual or psychologically informed concepts, however this thesis also values the relational and social circumstances that influence the experience of grief and bereavement.

2.6.1. Attachment history and psychological predisposition to complicated grief

The human capacity to form early attachment bonds with caregivers and the experience of this care was described by Bowlby (1980) as being fundamental to an adult's capacity to cope with relationships later in life, including the loss of someone close following death. For example, those suffering extreme forms of deprivation during their infancy might be expected to develop an insecure attachment style (Parkes, 2006). This identification of early infant experience and its influence on adult emotional and psychological strength or vulnerability, forms the basis for attachment-based counselling and therapeutic approaches (Fonagy, 1991) including a NICE (National Institute for Clinical Excellence, 2018) evaluated treatment for depression, dynamic interpersonal therapy (DIT), (Lemma, 2014). Adults are seen as carrying within them a set of assumptions about what to expect from their close relationships, which has a fundamental effect on how they respond within relationships. For example, having an 'avoidant' attachment style can predict a tendency to avoid closeness with others, including expressions of grief, which can lead to delaying or denying expressions of loss such as emotion including crying which can reduce opportunities to receive support from others (Parkes, 2006). The Adult Attachment Interview (AAI) (Main, 1984) is regarded as a reliable measure of the lasting influence of childhood attachments into adult life and is the basis for more recent work that seeks to identify an adult's vulnerability to having complex grief reactions following a death or other life losses (Shear and Gribbin Bloom, 2017).

2.6.2. Continuing bonds and the relationship to the deceased

Bowlby (1980) proposed that the pain of grief leads to a reshaping of internal representational models developed from infancy and that these continue after death affecting the quality and outcome of adult grief. The negotiation of what the deceased meant during their life and the subsequent change or re-working of the relationship to the deceased is described as a key dimension of grief (Walter, 1999). This revised understanding of how the bereaved continue to relate to those who have died has been termed the continuing bond (Klass et al., 1996). Bowlby (1980) understood this attachment bond as having an adaptive value linked to the development of new meaning and an ongoing sense of identity after a death, for example that widows and widowers that are able to let their "feelings of attachment to the dead spouse to persist" find "their sense of identity is preserved and they become able to reorganize their lives along lines they find meaningful" (Bowlby, 1980, p. 98).

2.6.3. Anticipatory grief and advance care planning

Anticipatory grief is the grief experienced by family members before the death of a loved one (Strada, 2013) and can predispose for a better grief outcome (Stroebe et al., 2007). The care offered for the families before the death can enable the exploration of the future death as well as the expression of feelings to and about the person who will soon die and that as a 'planned death' there might be a positive outcome if some form of 'pre-bereavement' preparation can take place. When an impending death (due to a terminal diagnosis) is discussed with the family in advance, some planning is enabled, having a more positive impact upon bereaved family members (Coelho and Barbosa, 2017). However, there is a need to have good quality information to be able to process significant events relating to the death, and to feel that they have had a satisfactory standard of support from the medical staff (Cleiren and Zoelen, 2002). Waldrop (2020) discussed how better preparation for bereavement occurs when families are supported well during the later stages of care for their deceased relative. There appears to be a link between well supported advance care planning involving families, with less aggressive medical treatment at the end of life and a positive affect for the bereaved (Wright et al., 2008).

2.6.4. Disenfranchised grief and stigma

Disenfranchised grief is a term used by Doka (1999) to describe how society's view of a relationship or person can be negative, which then devalues the loss of that person. Doka (1999) gives weight to the importance of the social influences on grief, using examples of grief following a death due to HIV or AIDS, which then contributes to the bereaved persons difficulty to express grief with others for fear of judgement. Death following suicide is included as a bereavement likely to inhibit social sharing and therefore lessening the available social support.

Having less social support is associated with greater social isolation, which is seen to be a risk factor for poorer outcomes in grief and bereavement (Stroebe & Schut, 2001, Wimpenny et al 2008). Following a study of over 450 parents who were bereaved by suicide, Feigelman, Gorman, & Jordan, (2008) confirmed earlier work by Dunn & Morrish-Vidners (1988) that found the suicide bereaved self-identify as stigmatised by others, were likely to assume that others would judge them, perceive the reactions of others as negative, and might avoid contact with others to avoid this expected rejection. This self-stigmatisation had also been noted by Jordan (2001), Cvinar (2005) and McIntosh (2011) and is discussed further in Chapter 6 (Literature Review).

The continuing bond can be more challenging and complex for the bereaved following a suicide with the corresponding emotional experience of feelings such as guilt, shame or anger along with the other feelings of grief such as sadness (Klass et al. 1996). The persistence of guilt is thought to be more likely following a bereavement by suicide and Rando (2002) also notes the quality of rejection that the survivor feels towards the deceased who can be felt to have chosen to leave or reject them by taking their life, and this can extend to feelings of being punished by the deceased (Séguin et al., 1995).

2.6.5. The dual process model

The dual process model (DPM) was developed by Stroebe and Schut (Schut, 1999) to overcome some limitations emphasised in the phase models of grief. Stroebe and Schut (2015) have extended their understanding of the dual process model from the individual to the family or group level, explaining how family members may grieve differently and may be affected by the social context of their grieving, giving it relevance in the consideration of the social and family dynamics that might be at work. This revised dual process model describes how parallel and interconnected loss and restoration-oriented tasks unfold and in turn influence and is influenced by the other.

Phase models are implicit in the work of John Bowlby (Bowlby, 1980) whose work has been highly influential in the development of the understanding of human attachment, love and loss (Parkes, 2006). Phase models can be criticised as being limited by imagining a linear psychological movement across time, implying either movement forward or pathologizing any delay or return to any earlier stages of distress connected to the loss. For example, Bowlby (1980) describes four stages from numbing, to yearning and searching, to disorganisation and despair, and finally to “greater or less degree of reorganisation” and the capacity for a positive life (Bowlby, 1980 p.85).

Offering the capacity to capture a dynamic and ongoing process of grief, the dual process model is based on stress coping models (Folkman, 1997; Lazarus et al., 1984). The dual process model imagines the process of coping with grief as having two kinds of stressors, named as loss and restoration-oriented coping, with an emotion regulation coping process oscillating between these two places.

The focus of the bereaved individual or family (Stroebe and Schut, 2015) in loss orientation involves processes of confronting the event of the loss, working to accept the loss for example by visiting the body and attending the funeral, and later by reminiscing about the person, including visits to the grave or memorials. The dual process model is imagined as containing interconnected tasks of coping associated with acceptance, pain, adjustment, and moving on, and that these may take place with either a loss or orientation focus (Stroebe and Schut, 1999).

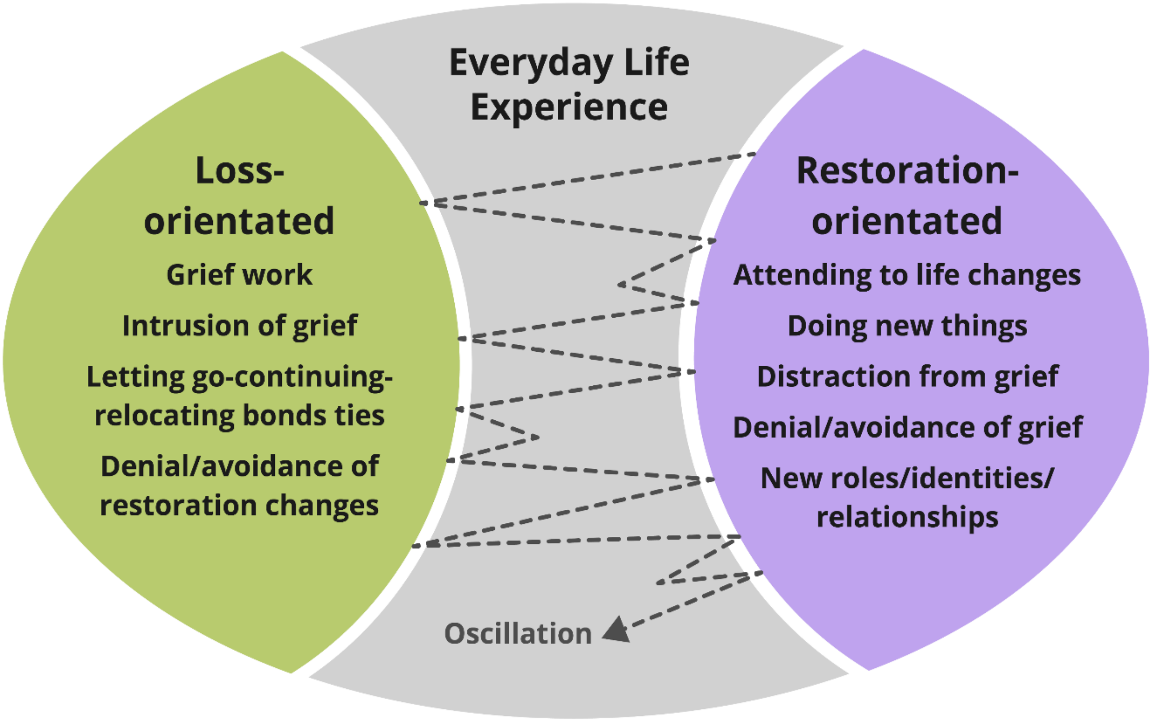


Figure 1. Adapted from the Dual Process Model of Coping with Bereavement (Schut, 1999).

The loss orientation side of the dual process model supports theories that the bereaved are required to confront the reality and implications of the loss, or to do the ‘work’ of grief (Freud, 1917), involving preoccupation with thoughts of the lost person, and continual and painful recollections of the experience of the death as the bereaved attempt to make sense of the death or loss including what the person means to them. This corresponds with the experience of searching and yearning (Bowlby 1980 p.85) and offers an understanding of how individual reactions to loss can be affected by the quality of infant attachment, described as secure or insecure, and that our early experiences as an infant affect our adult attachment style and influence how we grieve (Parkes, 2006).

Restoration-oriented activities are those relating to any life changes or implications that have come about because of the death or loss, for example, moving to a new home, or new relationships. Both restoration and loss-orientation can be sources of stress, having emotional consequences, for example, the anxiety caused by taking on new tasks after a family member's death, but can also introduce new positive possibilities such as building confidence in new skills and roles. This restoration activity can be likened to the rebuilding of a new internal assumptive world (Parkes and Prigerson, 2010) and as part of the psycho-social transition (Janoff-Bulman, 1992) that takes place after the subjective individual world of meaning that each of us builds, is threatened by trauma, loss and change. Restoration-orientated activity would be activity that operated to allow the remaking of a world without the loved person.

The description of chronic or absent grief reactions aligns with theories that attribute individual differences in adult grieving to earlier attachment patterns. Parkes and Prigerson (2010) describe how people who become preoccupied with the search for the lost person, those who stay primarily with loss orientation, might be described as having an anxious-ambivalent or dependent style of insecure attachment. Whilst those who may be avoidant of loss orientation, possibly using only restoration-oriented activity as a way of grieving, might be described as having an avoidant attachment style (one where early parental responses have discouraged emotional demands), making these people more comfortable with a controlled emotional response and with cognitive attempts at problem solving. Where there is lack of flexibility there can be a pattern of grieving described as showing an insecure attachment style, whereas the flexibility between both loss and restoration orientation activity indicates the capacity for a more secure attachment style or grief, where both loss and change can occur.

2.7. Access to bereavement support following AS

Although hospices and some hospitals in countries with a permissive framework for assisted suicide, are beginning to recognise their involvement and responsibility to these bereaved (Beuthin et al., 2021), those clinics offering AS in Switzerland currently give no ongoing follow up or support to families after the death has occurred (Bosshard et al., 2016).

In preparation for this thesis, an initial investigation was carried out to identify key stakeholders and explore what is known about the experience of or needs of these bereaved.

This included contacting the leading national bereavement organisation, Cruse; the national hospice bereavement organisation, Association of Bereavement Service Co-ordinators (ABSCO) and the British Association for Counselling and Psychotherapy (BACP) but none had any current policy or research guiding care for this specific group of bereaved people.

The health care services that are available to people living with a life-limiting illness, such as oncology, palliative care teams or hospices, may have varying degrees of comfort with physician assisted suicide. These groups may not be aware of, have considered or feel it is appropriate to consider how best to include those bereaved by AS in their bereavement care services. Although limited legal action has been taken towards those who are involved in an assisted death at the Dignitas Clinic (Crown Prosecution Service, 2014 and 2021), UK citizens bereaved in this way may be likely to have distanced themselves from palliative care agencies or other medical health and social care professionals for fear of prosecution or judgement.

2.8. Healthcare professional and assisted suicide

The British Medical Association (BMA) have sought opinions from their members and more recently the public, to form their policy on different forms of assisted dying, including physician-assisted dying, moving from their initial stance in the 1950s of outright opposition to euthanasia. In 2016 they took a neutral stance but since then they commissioned a review of members with further discussion planned for the next annual representative meeting (ARM), (British Medical Association, 2021). There appears to be a shifting position in this UK organisation towards legalisation. For example, to the question “Do you personally support or oppose a change in the law on prescribing drugs for eligible patients to self-administer to end their own life?” there was 50% support, with 39% opposed and 11% undecided (British Medical Association, 2021). The BMA do not lobby for or against a change in the law, continuing to ‘represent the views, interests and concerns’ of members but ‘insisting doctors must have legally protected rights to object conscientiously to participating, should there be a change in the law’ (British Medical Association, 2021). The Royal College of Nursing (RCN) currently also adopts a neutral stance on assisted dying, issuing clear guidelines on the legal position in the UK, suggesting good practice for how nurses practice end-of-life care, discuss advance care directives and respond to a request from a patient to hasten their death (Royal College of Nursing, 2014). This document is a second edition (Royal College of Nursing, 2016) and is currently under review following the last RCN conference in May 2021.

2.9. Background overview and conclusion

I have described the legal and social circumstances of AS in the UK and across the world and considered the limited research about the experience of those bereaved by AS. I then reviewed the theories and models of grief and bereavement and considered how those might also support understanding of these bereaved including those bereaved by suicide, ending with a brief review of the limited support for these bereaved.

A qualitative study would allow exploration of this population in the UK, whose experience has been little recorded. It would give insight into aspects of the experience of being bereaved by AS and how this might differ from other bereavement experience including those bereaved by other forms of suicide and how best to support these bereaved.

Within the UK and in other parts of the world without a clear legal framework for assisted dying, there are ongoing discussions and debates within social, professional and legislative organisations that both support and challenge a change in the law to enable this (Box and Chambaere, 2021). As this debate continues this research will offer insight into the experience of people close to those choosing to die in this way and will consider how this might affect them both during the time leading up to the death and afterwards.

Chapter 3. Methodology

This chapter includes a review of the purpose of the research including rationale, outlining the methodological approach using constructed grounded theory (Charmaz, 2014). The ontological and epistemological assumptions that lie within the methods used in this research are discussed.

3.1. The research question: How does assisted suicide affect the experience of the bereaved in the UK?

This research seeks to explore how AS affects the experience of the bereaved using constructed grounded theory as a methodological approach to the collection of data and the techniques for analysis. Constructed grounded theory will be used to build an understanding of the phenomenon of a UK citizen becoming bereaved following AS in a country that has a legal framework to support this kind of death.

The research seeks to explore what these bereaved people experience and contribute to the debate about assisted dying and suicide, giving attention to the care of the bereaved alongside the consideration of how this might be regulated in the UK. Although this is a small group of people, as legislation changes this number is likely to grow. However, both the deceased and the larger number of bereaved (Dignity, 2021) have been given little attention by researchers or professionals in the care of the bereaved (Gamondi, 2013). They may be expected to have more complex or complicated grief reactions (Bascom and Tolle, 1995; Beder, 1998; Wagner et al., 2012).

3.2. What is known about the experience of these bereaved?

There is limited research about the experience of bereaved people due to AS, (Gamondi, 2013) and none relating to people living in the UK and it is helpful to find an approach that will allow new concepts to be developed to help understand this new phenomenon. This limited research about those bereaved by AS has used different methodological stances and methods, having reached divergent views about the relative psychological or social risks to the bereaved. The literature about grief and the risk of complicated or prolonged grief is wide and has been preoccupied with attempts to define, measure and predict risk of mental health outcomes following bereavement.

Research on those bereaved by assisted suicide in the US State of Oregon, by Ganzini et al., (2007) find no increased risk of complicated grief, except when there was the associated issue of the absence of perceived (by the bereaved) social support. This study relies on a small sample group despite using quantitative methods, and as the results are expressed using statistical data are likely to find small differences that might be attributable to the lack of participants and relative lack of power in the research design, however the study is useful as it identifies how social support may be important for these bereaved.

A qualitative approach to this study enables the exploration of issues that arise for the bereaved following assisted suicide in the UK, both from a social and individual perspective. Walter (1999) challenges a purely psychological account of grief by arguing that powerful social forces affect both the shaping and expression of individual grief. The process of grieving can also be imagined as a psycho-social transition by which those newly bereaved need to orientate themselves within a world where much of the meaning has changed due to the death (Parkes 1993, Janoff-Bulman, 1992). A systematic literature review of those bereaved by physician-assisted suicide (Gamondi, 2019b) found that social context appears to have a significant effect on the individual experience of not being able to share their experience with others due to the social taboo that surrounds suicide. A qualitative approach to this research can give important information about the territory of the personal difficulties, as well as the social terrain surrounding the experience of these bereaved people.

3.3. Finding a theoretical framework that enables the best response to this research question

Walter (2006) questions the cultural specificity of grief reactions and suggests there are structures at work, creating discourses and events that affect the experience of bereaved people. Doka (1999) discusses the unhelpful influence of social attitudes to some deaths on the individual experience of grief in his work on disenfranchised grief. For those bereaved by an assisted death there might be similar social taboos in place to those deaths that occur from suicide, or for deaths associated with illegal acts.

Bereavement following assisted suicide is likely to become a growing social phenomenon and to consider the needs of people affected it is helpful to consider the social as well as psychological aspects of experience. A constructivist grounded theory approach (Charmaz, 2006) would give the opportunity to look more closely at how the social meaning of their experience is both created by the bereaved and affects the bereaved, offering an important avenue in understanding the relationship between the individual and social experience of grief (Valentine, 2007).

Grounded theory pays close attention to the actions and processes to create theories with the capacity to explain social experience (Glaser and Strauss, 1967; Strauss and Corbin, 1990; Strauss and Corbin, 1998). This is particularly useful as there are currently few existing theories that might support better understanding of the experience of bereavement following AS. Strauss and Corbin (1998) define this capacity as 'theory that was derived from data, systematically gathered and analysed through the research process. In this method, data collection, analysis and eventual theory stand in close relationship to one another.' (Strauss and Corbin, 1998: 12). Grounded theory works closely with the data, in both collection and analysis, in an iterative way, enabling the findings to be closely grounded in the newly emerging themes (Strauss and Corbin 1998). It is hoped that it is possible to develop new conceptual categories by drawing on both the narratives and descriptions found in the data.

Grounded theory, with its roots in symbolic interactionism focuses on the way in which people make sense of social interaction and allows for the study of social processes and structures (McLeod, 2011). This is important for an enquiry into a kind of death that is currently new to society, and seemingly heavily influenced by a polarised debate about AS. Grounded theory is typified by approaches to method, for example the generation of categories, properties, and concepts, rather than attempting to test any hypotheses. As the research unfolds, and the basic 'problems' for the participants emerge, grounded theory can allow opportunities to discover the process participants go through to cope and resolve this problem (McLeod, 2011). For instance, the 'problem' of arranging AS undertaken in a foreign country and with unclear legal guidelines in the UK, is likely to affect how relatives might experience this kind of death, and therefore grounded theory seems to offer the opportunity to understand both the personal and social experience of this relatively new phenomena.

Constructed grounded theory takes this capacity to pursue both social and psychological aspects of the experience of these bereaved further, by acknowledging the importance of the personal experience and assumptions of the researcher, giving additional ways of understanding the creation of these findings. See section 3.7. for further discussion of reflexivity and constructivist approach within this thesis.

3.4. The early development of grounded theory and awareness of dying

In 1967 Barney G Glaser and Anselm L Strauss collaborated in the publication, The Discovery of Grounded Theory - Strategies for Qualitative Research, in which they outline the development of a new approach to understanding both research methods and methodology. This work developed out of research with patients, their families and health care professionals about their awareness of dying within the health care system of the United States in the late 1960s (Glaser and Strauss, 1965). They looked in careful detail at these groups of people describing the social processes used to manage communication with patients and families about their terminal prognosis. Chapters such as 'The Ritual Drama of Mutual Pretence' shows how they used close observation of dialogue to develop useful descriptions of social processes, for example, "One nurse who worked on an intensive care unit remarked about an unusual patient in that he had announced he was going to die: 'I haven't had to cope with this very often. I may know they are going to die, and the patient knows it, but [usually] he's not going to let you know that he knows'." (Glaser and Strauss, 1965, p64). However, in the final two chapters they go on to support their claim of having developed a 'substantive sociological theory' (Glaser and Strauss, 1965, p259) by making a clear outline of their methodological stance and how this is embedded and expressed by their carefully carried through research method.

In the Appendix to the book Glaser and Strauss (1965, p286) claim that the concepts involved in this theory of awareness of dying, such as 'mutual pretence' or 'open awareness' were credible because they were both 'analytic – sufficiently generalised to designate the properties of concrete entities' but also 'sensitising – they yield a 'meaningful' picture – with apt illustrations which enable one to grasp the reference in terms of one's own experience' (Glaser and Strauss, 1965, p291). In this way, they describe their journey to the development of grounded theory in relation to this important work on the awareness of the dying patient, but they also demonstrate how the highly charged and emotive subject of dying and the care of the dying is profoundly affected by the social setting of those ‘actors’ involved in this ‘mutual’ process.

3.5. Recent developments in grounded theory and how this informs research methods

Glaser and Strauss discuss how by becoming immersed in the data it is possible to ‘discover’ and generate explanations of phenomena that were grounded by reality (1967). Grounded theory uses an approach to knowledge that assumes and values objectivity to create research methods that strive for replication and generalisability to falsify competing hypotheses (Strauss, 1987). As part of the growing sociological research taking place in the United States and United Kingdom in the 1940s and 1950s, using life history, case study and participant observation methods it became increasingly challenging for qualitative research to assume a positivist paradigm (Bryant and Charmaz, 2007).

An important development to grounded theory comes from Kathy Charmaz (2014) who challenges the approach to grounded theory of Glaser and Strauss (1967) and Strauss and Corbin (1990) describing this as an endorsement of ‘mid-century assumptions of an objective external reality, a passive, neutral observer, or a detached, narrow empiricism.’ (Charmaz, 2008, p137).

Later work by Charmaz (2014; 2017) introduce a challenge to this positivist position by acknowledging the role of the researcher in the construction of the findings of the research. For example, a constructed approach (Charmaz, 2014) acknowledges the need to make a later use of a literature review, however they assume the researcher’s mind is full of ideas, preconceptions arising from their professional knowledge, or perhaps their social status or class, and that these need to attempt to be ‘turned off’ or at least taken note of. Glaser and Straus (1967 p.76) claim that “everything was data”. However, when meaning-making during data analysis, constructed grounded theory challenges that view, asking ‘is data is everything?’ arguing that the researcher’s role in the construction of the meaning-making must be considered (Charmaz, 2014, p.89).

3.6. Reflexivity and a constructivist view of the research process

A constructed grounded view of theory enables the researcher to take account of their worldview in the development and construction of meanings derived from the data via the analysis and then presented by the research (Bryant and Charmaz, 2019). An approach using grounded theory takes account of the sensitive nature of assisted suicide in people's lives, and the influence of society, which includes the researcher, on the narrative and description of their experience. By using the social construction of meaning, the researcher will pay close attention to the interaction between these influences and personal experience.

This approach to grounded theory stresses the reflexivity of the researcher, which is particularly important when endeavouring to research the highly personal subject of AS. Charmaz (2014, p.14) views both the 'knowing and doing' of the researcher 'as embedded in social life' and that 'subjectivity is inseparable from social existence'. For example, a researcher meeting those involved in the current debates about assisted dying in the UK, would be likely to find it difficult to engage in a meaningful way without being influenced by the passionate arguments taking place that are either very supportive or very critical of permitting assisted dying. Constructed grounded theory requires researchers to carry out an ongoing process of reflection. This careful attention to reflexivity is also seen as particularly important for researchers who are working with vulnerable participants such as the bereaved (Stroebe et al., 2003; Valentine, 2007).

Charmaz describes, during a filmed conference interview, the endeavour of reflexivity to 'control the flow' rather than to 'turn off' prior knowledge (Gibbs, 2015). Giving careful attention to reflexivity, I have kept a reflective journal that begins with my initial position on assisted dying, so that this informs my capacity to understand the part I play in the co-construction of the meanings, concepts and any theory building that might become possible as the research continues. For example, it is helpful that for this research that I am prepared and able to talk about death, dying and bereavement because of professional experience working in hospice and bereavement services.

I use memos and ongoing reflections in my journal, along with reflections during external non-academic clinical supervision and academic supervision because to research in a world that you already have experience of requires attention to bias and a participant data-centred approach. Reflexivity is undertaken to understand the possible influence there might be on the research from my work experience as a provider of bereavement support, a psychotherapist using psychodynamic counselling approaches, and the manager of a bereavement service who has a responsibility for the assessment of clinical risk. There also needs to be reflexivity in relation to my personal experience as the daughter of an aging father over 90, as a woman in her late 50's and later as a bereaved daughter.

Public discussion and the legal arguments about assisted dying have become characterised by having polarised positions (Fontalis, Prousali and Kulkarni, 2018) and I needed to be particularly mindful of how this might affect my approach to the research. For example, the design of the semi structured interviews used 'open' rather than 'closed' questions, helping participants to focus on issues that were relevant to them (Weller et al., 2018), without the introduction by the researcher of pre-supposed themes. The interview questions have avoided using words that might be felt to contain value judgements within the debates currently taking place. For example, terms such as 'dignity' are used by campaign organisations (Hendry et al., 2013) and can be argued to imply that the right to choose an assisted death equates to a dignified death. This term was excluded from interview questions within the semi-structured participant interviews as it might be considered to pre-suppose that an assisted death had resulted in a more 'dignified' death although that might not have been their experience and might close their opportunities to voice a different experience. In a similar way although the current law within the UK is part of that relating to 'suicide' (Van Bulck et al., 2022) the research question used during recruitment did not use the term 'suicide', instead using 'assisted dying' as the term 'assisted suicide' could have introduced notions of stigma (Nicolini, Gastmans and Kim, 2022).

Constructed grounded theory assumes a structural view of the world (Charmaz, 2014) by which structures are constructed by the actions of participants who can either keep the structure in place or change the structure by repeating actions or change in action. This kind of analysis of in-depth interviews can be viewed as a heuristic device, having a practical application for learning about the world, as the researcher looks at incidents or processes, whereby an incident is thought of as any action that leads to an outcome. In relation to this research question, there is analysis of the actions described by participants, for example, deciding to have an AS; the actions of those close to the deceased when they decide who is told about the impending death and who is not; the action and processes of arranging and taking the journey; the event of the death; the disposal of the body; the actions taken just after including how soon to return to the UK, and any actions taken since then in relation to the kind of death that was experienced.

3.7. The literature review and the epistemological position of this research

Grounded theory recommends that the literature review takes place at a later point in the research process and is not the initial piece of work undertaken as a starting point for all aspects of the research. This attempt at 'theoretical agnosticism' is criticised by Henwood and Pigeon (2003, p.138) for assuming everything known can be set aside by the researcher so that the mind is a blank slate with no prior or subjective knowledge. Public discussion and the legal arguments about assisted dying are characterised by the polarised positions of these arguments about legislation of this kind of death in the UK and it would be difficult for anyone to be 'naïve' of some of the emotionally charged stories of people who have chosen this kind of death and have appeared in the press and television. Even without a literature review the researcher might easily be led to use the existing 'concepts' that appear in the media which might affect the ways in which I, as the researcher, might frame or respond to questions in the participant interviews. Charmaz (2014) recommends the researcher prepare for the research topic by developing 'sensitising concepts' (2014, p.30) to help the researcher fully enter the world and understand the views of the actors.

3.7.1. The use of literature in a constructivist grounded theory methodology

The researcher values the constructivist grounded theory method for the capacity to theorise from the data, rejecting the notion of objectivity from Glaserian and Straussian perspectives of grounded theory. Instead, agreeing with Charmaz (2014, p.239) that 'theory depends on the researchers view: it does not and cannot stand outside of it', I chose constructivist grounded theory with its assumption of subjectivity. It follows that the use by the researcher of extant theory and earlier research findings, for example from literature reviews is viewed differently from Glaserian, Straussian or constructed grounded approaches.

3.8. Reflexivity and the use of literature within the study

Using a constructed grounded theory perspective this research uses a reflexive and pragmatic approach to theory with existing theory, models, or frameworks ‘earn(ing) their way into your narrative’ (Bryant and Charmaz, 2007, p. 126). Methodological approaches to the analysis of the data are drawn from participant interviews alongside early ongoing engagement with relevant literature and are used to create an iterative cycle.

Constructed grounded theory methods used include reflexive memo-writing, theoretical sampling and constant comparison (4.8). Memos are an important tool used alongside the use of literature within this research study to record how pre-existing studies have been both understood and influence the development of theoretical concepts within the study. Ramalho et al. (2015) describe the use of memos as an aid or tool to the researcher allowing “the engagement of a theoretical dialogue with the data, without allowing such literature to define the research” (Ramalho et al., 2015, p.21).

A constructed grounded theory approach welcomes the use of literature throughout all stages of the research (Charmaz, 2014). Firstly, an initial review to both broadly inform the study and to locate the researcher to the subject area, contributing to the background reading and chapter. Even from this early stage a sceptical stance is taken towards any findings, theory, or assumptions within the field. This use of constant comparison (Charmaz, 2014) was to aid the early development of concepts and this ongoing and iterative process continued and became part of the development of theoretical sampling. For example, the tentative expression by some participants of early ambivalence towards the decision for AS led to reading of literature about grief and bereavement developed from attachment theory (Parkes, 2006). However, close reflection aided by using memos enabled the researcher to pay close attention to their own personal experience as a bereavement counsellor influenced by training embedded in psychodynamic theories including attachment that might derive from too narrow a perspective. Further literature and reading were sought that addressed theories of caregiving from other perspectives and this enabled a more balanced focus that included the social context of the experience.

Thirdly a critical interpretive review of literature, will contextualise the findings locating this study within and across other disciplines (see Chapter 6. Literature Review).

3.9. Summary

By bringing clarity to the methodology, I hope to demonstrate the capacity of constructed grounded theory to be reflexive, enabling me to question any ontological assumptions that might arise from the social or individual realities that take place around AS, and how these affect the findings and analysis within this thesis. The next chapter describes how this aim is operationalised using methods that align with a constructed grounded approach.

Chapter 4. Methods

4.1 Introduction

A constructed grounded theory approach guided the methods used to carry out all the procedures within this thesis. In this chapter I describe the methods used to carry out the description, analysis and interpretation of the data (Wolcott, 2009), including sampling, recruitment, ethics including data collection, storage and management of confidentiality, interviews, coding, and use of memos.

4.2. Population under study and eligibility criteria

Thirteen adult participants were interviewed to gain insight into the experience and needs of those bereaved in the UK by AS. Care was taken not to recruit subjects who had assisted a suicide taking place in the UK in case this endangered safeguarding and confidentiality. People whose relatives had died from AS or euthanasia in the UK were excluded as this is illegal in the UK and the participant and the researcher would have been legally comprised and the researcher unable to maintain confidentiality. They are also likely to have had a different experience than those whose relatives travel abroad. The clarity of the inclusion criteria aimed to enable the researcher to ensure that only those meeting these criteria were contacted for further information (Aveyard et al., 2021). Participants were recruited who had become bereaved within longer than the preceding six months, as this length of time has been understood to give participants time to move from the earlier phase of grief which might make participants particularly vulnerable (Valentine, 2007).

The study excluded children under 18 bereaved by AS, as the experience of bereaved children merits special consideration outside of the scope of the research question. It also excluded those who had experienced the loss of a child under 18 as there is evidence to suggest that the effect of the death of a child under 18 merits a specific area of study which is also outside the remit of this research (Stroebe and Schut, 2015).

Table 2. Research Inclusion and Exclusion Criteria

Inclusion	**Exclusion**
Over 18, male or female, living in the UK	That the death has taken place less than six months ago
Participants will have experienced multiple or single deaths of a family member or friend occurring by AS	A death that took place in the UK
A death taking place in a country that has a legal framework to allow an AS	

4.3. Recruitment of participants

The views of early informants were sought leading to guidance in how best to recruit these participants and included meeting with a wide range of experts and those with experience of AS who are based in the UK. A snowball approach was used by asking informants and participants to suggest other people that might be helpful in recruiting further participants. Organisations approached were those that would firstly have been likely to be accessed by the family member in the UK using AS, for example the campaigning organisation Dignity in Dying (2021), which led to successful recruitment. Contact with organisations campaigning against AS, Care Not Killing (Care Not Killing, 2021) and Not Dead Yet (Not Dead Yet, 2021) was also made which informed the development of the research, however this did not lead to any recruitment.

Flyers describing the research with a link to a research website were distributed via organisations and at events including specialist conferences and events on AS. Social media tools have also been used to recruit participants, for example a Twitter account was set up with followers in organisations that were likely to include those bereaved by assisted suicide. Requests were made to organisations with numerous followers to pass on the information about the research project to their Twitter followers, for example Cruse Bereavement Care. Presentations were made to conferences that asked for feedback about the research question and to advertise for participants (Appendix K). This led to many contacts within this field which informed the research and led to three word-of-mouth introductions, however most recruitment has taken place via the charity, Dignity in Dying (Dignity in Dying, 2021b). The implications of this bias in recruitment is discussed in 8.3. Limitations and Strengths of the Study.

Initial contact was made through publicity or by snowballing via an introduction, and an initial email (Appendix A) was sent with the Participant Information Sheet (Appendix B) and a Consent Form (Appendix C). The Participant Information Sheet (Appendix B) described the aims and objectives with a clear outline of the research methods and data collection methods including a description of the interview process, including how long it is expected to take and careful explanation of how the data is intended to be used in any future publications or dissemination, including how quotes or case study material will be kept anonymous.

4.4. Ethical issues

The researcher has a clear duty of care to protect the participants both during and after the research project and provided clear information and procedures to enable this with information about the study was provided to participants to enable informed consent. There were no financial incentives to participating in this study. Confidentiality was carefully maintained during and after the research project and the means to secure this was explained in the information given to participants. Issues of anonymity and confidentiality were considered at some depth as these participants came from a relatively small group of people in the UK who belong to one or two campaigning organisations. Saunders et al. (2015) recommend that particular care is taken with some potentially sensitive information and for this research, first names, places and family relationships were anonymised and some potentially identifying information or quotes were changed or excluded.

The illegality of AS in the UK makes discussion or research ethically and legally challenging. In the UK, it is currently illegal to encourage or assist suicide or an attempt at suicide. However, public interest factors were included in the Participant Information Sheet (Appendix B) for guidance which consider factors such as did the ‘victim’ have capacity, or had they come to some written arrangement about their decision (Crown Prosecution Service 2014). Legal guidance was given to participants so that they were in a better position to decide if they wished to take part in the research.

Areas of sensitivity for participants can arise for those who have had a bereavement and the issues arising for this group have been discussed by other researchers (Stroebe et al., 2003; Valentine, 2007) and were used to guide the research. The Participant Information Sheet (Appendix B) gave information about the possible effects that might occur and included debriefing information that gave advice about how best to make efforts for self-care and how to seek further support if necessary, such as finding bereavement support nationally and locally.

The Consent Form (Appendix C) asked that participants sign to confirm they understood the information given and sought permission for the recording and transcription of data, giving information about how and for how long this will be stored. This also explained how and for how long information about their personal details will be kept and who will have access to this data, and in what form by clinical and academic supervisors who may see data after it has been made anonymous.

The project was approved by the Research Ethics Committee at Lancaster University and meets the requirements of the EU General Data Protection Regulation Protection Act (EUGDPR, 2016).

4.5. Data Management and Storage

The recording took place on a recording device and these files were uploaded immediately after the end of the interview to a computer with an encrypted password. These digitalised audio files are kept on an encrypted, password-protected computer. These are backed up to an encrypted hard drive. During transcription from audio to written format, the data was made anonymous in relation to names of people or places. Further care takes place during preparation for any publication in case any details, quotes or case study information which might inadvertently allow identification of a participant. All personal details are encrypted and kept separate from the anonymised data and will be destroyed once the thesis has been assessed. The original hard copies, interview notes, any letters, and downloaded audio tapes will be stored for five years and kept securely in a locked filing cabinet.

4.6. Sampling

As the recruitment continued it became clear that most of the participants came via campaigning organisations that were in support of assisted dying. Snowball sampling was then used which aimed to lead to interviews with different members of the same family which might allow exploration of the differences in views between family members, and possibly the opportunity to explore the differences between experiences relating to the degree of involvement in the choice of and presence at the assisted suicide. This led to the recruitment of two of the participants who were friends of the deceased. However, this was not successful in recruiting people that were close family members, and this is discussed in 8.3. Limitations and Strengths of the Study.

4.7. Interviews

Audio interviews were carried out using an encrypted recorder. The researcher informed the participant at the outset that they expect this to take between an hour and an hour-and-a-half. The semi-structured interviews have taken place face-to-face. A semi-structured guide to the interview used open questions, hoping to elicit flexible responses, giving participants the opportunity to talk about any aspect of their experience of AS. This accords with a constructed grounded approach being more likely to avoid too early a focus by the researcher on some descriptions, processes, actions, or values at the expense of other areas of experience. (See Section 3.7.).

4.8. Data Analysis

The identified steps for a constructivist approach to grounded theory methodology are initial coding, including in vivo coding; focused coding; the process of constant comparison; the use of memos and theoretical coding leading to the creation of overarching theory (Charmaz, 2014).

4.8.1. Initial Coding

Initial coding involved the researcher making a close reading of the transcription, searching for initial impressions and repeating processes, and relationships between these processes including attention to gerunds, the active verbs used by participants to describe their experience. Word-by-word analysis was undertaken for the first five interviews to build initial meanings. Initial coding took a line-by-line approach, where the researcher takes an active role to identify and note codes that stand out and that develop from the data (see Appendix D). The researcher is selective, but also reflects and writes memos about the initial impressions and personal reactions as these initial meanings are made. This was an active process of sorting and condensing into emerging meaning.

The coding is a process of creating a larger story in relation to what the codes might tell the researcher. This is a process of taking descriptive codes that become analytic as the description is broken up. This process included the creation of 'in vivo' codes. In vivo codes are phrases or words occurring frequently given weight by the participants and following reflection by the researcher in the analysis. These 'codes that researchers adopt directly from the data (are) telling statements' (Charmaz, 2014 p.343). An example is the term 'a good death' used by some participants, which leads to consideration of the meaning and exploration of an everyday phrase, where the meaning might usually be taken for granted.

4.8.2. Focused coding and categories

Choices made by the researcher to move on to focused codes, where relationships between codes are further clarified, and are simultaneously or subsequently compared to the data is called 'constant comparison' (Charmaz, 2014 p342). Charmaz (2014, p.189) describes how categories 'explicate ideas, events or processes' in the data. As a code was raised to a category, the researcher made narrative statements that explained and reflected on the process within memos. These notes enabled the researcher to account for how the category was defined; the properties of the category; the conditions under which the category appears to arise, is maintained or changes and any apparent consequences; and lastly how this category relates to other categories (see Appendix E).

4.8.3. The use of memos

As part of the constructed ground theory approach, memos are used throughout the analysis of the participant's transcripts to document development of ideas about data, themes, and emerging conceptual schemes. Memos are informal analytic notes which enable the researcher to interpret the data by asking questions of it, and served to link up the data collection with the first drawing-together of codes into categories or codes. They allow the researcher to keep ideas that may not initially seem important but become so as analysis continues, encouraging reflection on patterns and relationships within and between categories and emergent conceptualisations.

Constructed grounded theory recommends the use of memos in a way that includes the part played by the researcher and the ongoing reflection of a journal or log, rather than only taking note of methodological issues. This is a process where memos record the empirical qualities of data and are taken from early on during line-by-line coding, focused coding and later during analysing, theorising, or writing and include both data and personal reactions to the data. The memos will be chronologically recorded so that they can be returned-to later, providing the possibility of grappling with concepts that may feel stuck and may not need to be objectively ‘accurate’, rather are subjective and might become theoretically useful. Glaser and Strauss (1967) focused on theoretical and methodological memos, but constructed grounded theory takes a different stance (Charmaz, 2014), valuing anything that strikes the researcher including gaps in codes, links between them, musings on usefulness or even perhaps early consideration of practical implications of this from a professional perspective.

Memos are also used to provide an audit trail and contemporary record of the ‘theoretical sensitivity’ developed by the researcher (Glaser, 2014). This is a term used by Glaser to convey the skills and growing experience of the researcher using grounded theory. Glaser discusses the importance of the acquisition of theoretical sensitivity via practice and professional experience and the researcher will be using her experience as a psychotherapist where she looks in some detail to the language used in an interview. Memos are private to the researcher, allowing for an unedited response to data, and introduced to supervisors or to the text when they feel relevant and useful (Charmaz, 2013).

4.8.4. Methodological memos

This is included in the research process to allow for epistemological reflexivity giving consideration of how well my methodology informs my method, where the researcher asks questions of their methodological decision-making, to encourage thinking about varied directions in the research and later findings, that will assist understanding of any assumptions and attitudes that might obscure understanding and affect meaning-making (see Appendix G).

4.8.5. Constant comparison and the analysis of meaning from within the data

An ongoing process of review was carried out, enabling constant comparison (Polit, 2012). Constructed grounded theory suggests that research might create an account offering the most extensive explanation and giving the greatest range of understanding. Charmaz (2014) suggests that if you have competing explanations these can be tested for strength against the data, meaning that concepts developed from the focused coding of the data might be taken and compared back again to the initial coding. One understanding of this epistemological position, typified by the earlier claims by grounded theory to induction or deduction from the data, can introduce instead the idea of abduction, by which some puzzling finding in the data might lead to a creative, imaginative leap by the researcher or researchers who attempt to put together a new way of accounting for the empirical findings or the range of possible explanations already suggested by the empirical findings or data. Reichertz (2009) describes this kind of reasoning as 'an attitude towards data and towards ones' own knowledge: data are to be taken seriously, and the validity of previously developed knowledge is to be queried. So, it is a state of preparedness for being unprepared' (Reichertz, 2009, p.221). See Appendix, F and G.

4.8.6. Theoretical Sampling

The 'constant comparative' method described by Glaser and Strauss was innovative in its iterative method, making data collection and data analysis as simultaneous activities for the researcher (Eaves, 2001). In this research project, there is a continual process of comparison to enable theoretical sampling so that the initial coding leads to more focused coding as emergent themes become clearer. Theoretical sampling is driven as the researcher develops theory and continues until no new codes are identified in the data with coding becoming more advanced and the researcher seeking out extant theory hoping to explain and give power to the integrative grounded theory that has been found in the real data. Saturation of categories from a constructed grounded theory approach is achieved by looking at the different ‘cases’ which might be plausible to varying degrees, and by using constant comparison until no new concepts emerge. Saturation relates to the theoretical concepts arising *in* the data, rather *than* the data, and the research expects some questions to develop a saturation of meanings or ideas as the researcher explores the range of variety within a concept or category. The links between these concepts will give further possible theoretical understanding as this research pursues abstract understanding, and the links and relationships between abstract categories become clearer. See Appendix H.

4.9. Overarching theory

Theoretical sampling is used to ask analytic questions of earlier codes developed in the interviews, so that the research can include further information and move on with the development of a category, considering further what constitutes the data and properties, as well as the conditions under which those properties emerge and helps define what the research is addressing. In this way language is seen as structuring and forming a frame for actions, and therefore greater attention is paid to the language used by participants. I approached the creation of an overarching theory by staying close to the data, whilst using theorising to ask questions of the data and continuing to strive to see possibilities or establish connections within the data that addressed my initial research question.

Charmaz (2014, p228) states that ‘theorizing accounts for the actions involved in constructing these accounts.’ The use of constructed grounded theory methodology enables this research to account for the relationships and social context that must be a predetermining background to any endeavour seeking to create new knowledge and insight into the experience of others.

4.9.1. Constructed grounded theory and relationship between researcher and participants

I recognise that the development of meaning is contextually based, also that multiple realities are possible within any endeavour to co-construct meaning. Constructed grounded theory also enables recognition of the mutuality that can exist within the research relationship between participant and researcher. Charmaz (2008) describes the nature of the possible research relationship as one of ‘Entering the phenomenon [which] shrinks the distance between the viewer and the viewed. Subsequently, we might better understand our research participants multiple realities and standpoints' (Charmaz 2008, p. 133). During analysis I was able to review my own standpoint and become more flexible in taking on these new views on assisted dying by using my personal memos and my supervisory discussions.

4.9.2. Constructed grounded theory and social context of researcher

Charmaz (2006), maintains that researchers can develop a detailed understanding of the underlying social or psychological processes within a certain context by exploring the detail of social interactions and social structures which may not be immediately apparent but emerge over time as the data is analysed and theorising begins. The development of mid-range theory is constructed between the participants' data and the interpretation made by the researcher, '. . . contextually situated in time, place, culture and situation' (Charmaz 2006, p.131). The process of development of theory was supported by both constant comparison and reflexivity, for example, see Appendix a,b,c,d & e. giving examples of figures that chart the development of theory, for example d. & e. show how the theory was further developed using the dual process model, and the first use of the dual process model to consider anticipatory grief.

4.10. Rigour and trustworthiness of the research

It is important to consider both credibility and dependability throughout the research process. During data collection the researcher listened closely and carefully to the obvious and less obvious meanings expressed by the participants about their experience. During data analysis the research process was carefully carried out with ongoing reflexivity, enabling integrity within and to the findings. Reflexivity was enabled by making memos that recorded both clinical and academic supervision, enabling full attention to the rigour of the approach used in the creation of new theory.

4.11. Summary

Considering the needs of the identified research question - how does assisted dying affect the experience of the bereaved in the UK - this chapter considers how this is best achieved by using a constructed grounded theory methodology. Rigorous attention has been given to research methods, taking account of a constructed grounded methodology, demonstrating the integrity of the findings described in the next chapter.

Chapter 5. Findings

5.1. Introduction

In this chapter I present an overview of the processes and actors involved in AS and how this affects the experience of those bereaved by assisted. The experiences of all participants are represented in this chapter, with quotation marks and italics and participant code. The person who died is described as the 'deceased'.

Table 3. Overview of participant characteristics

Participant Code No. and Participant Deceased Code Letter	F/M	Relationship to deceased	Travelled with deceased	Aware of plans before death	Member of Dignity in Dying (2021) or other pro assisted suicide campaigning organisation
P1/A	F	Daughter	Yes	Yes	Yes
P2/B	F	Partner	Yes	Yes	Yes
P3/C	F	Partner	Yes	Yes	Yes
P4/D	F	Daughter	Yes	Yes	Yes
P5/E	F	Sister-in-Law	No	Yes	Yes
P6/E	F	Brother	Yes	Yes	Yes
P7/E	M	Friend	No	No	No
P8/E	F	Friend	No	No	No
P9/F	F	Daughter	Yes	Yes	Yes
P10/G	M	Brother	Yes	Yes	Yes
P11/G	F	Sister	Yes	Yes	Yes
P12/H	F	Sister-in-Law	No	Yes	Yes
P13/I	F	Friend	No	Yes	No

The study includes 13 participants bereaved by AS. Twelve had relatives that travelled to Dignitas (7) and Life Circle (1) in Switzerland with 1 in Belgium. Dignitas (2022) and Life Circle (2022) are right-to-die organisations that welcome people from other countries to end their lives with AS. Some of the participants are discussing the deaths of the same person, with a total of nine people that have died from an assisted death.

All 13 participants expressed that they supported their relatives or friend's choice. Eleven of the participants knew about the planned AS in advance and of these 10 took on roles to enable the death. The role of enabling the death and the responsibility taken for the arrangements made to travel abroad to die was discussed in depth by these participants during the research interviews. Of those, 11 were involved in making the arrangements and 8 travelled with their relative to die. They sometimes travelled in small family groups of no more than four, but for six of the participants they were the only person to accompany the deceased and then returned alone (Table 3). The character of the person choosing the AS was often linked during the interview to a description of their character as well as to the diagnosis and possible trajectory of their illness.

There was always significant discussion of the experience of accompanying the deceased and what it was like to be present when their relative died. All but one participant returned the next day, leaving the deceased to be cremated and the ashes were later sent to them in the UK. Following the death, participants described how on returning to the UK they let a wider circle of people know about the death. This experience of having responsibility to arrange the AS took between six months and two years.

A constructed grounded theory approach is used to understand the experience of people bereaved by AS. Following analysis of participant interviews using a constructivist grounded theory methodology, there are six conceptual categories describing participant experiences which include a brief description of the actions, processes, and experiences of those bereaved by an assisted death.

Table 4. Categories, experiences, and accompanying processes

Chronological experience of events of the death	**Category**	**Experiences**	**Accompanying processes**
Decision for AS	The Feared and anticipated death	Anxiety and fear about anticipated death Isolation/Responsibility Suppression of sadness and opportunities for anticipatory grief	Protection of the deceased
Arranging the death	Honouring Wishes of Deceased	Anxiety about legal process Seeking advice from others with similar experience Business-like	Stigmatisation
Deciding when to travel to die	Enabling the AS	Anxiety – prevention of PAS Gatekeeping information Isolation	Stigmatisation
Attending the death	Accompanying and Witnessing	Distress and anxiety Painful journey Responsibility/Isolation Surreal experience	Maintaining suppression of feeling
After the death	Revealing the Death	Anxiety of return to UK/legal sanction Opening up Burden of telling others and their reactions	Memorialisation Relinquishing suppression of fact of assisted suicide Relinquishing suppression of feelings about experiences
Bereavement since the death	Campaigning	Opening up about experiences Seeking support from others with similar experience Public expressions of experience	Making meaning of the circumstances of the death Desiring change in law Challenging stigma of suicide

The development of these categories is guided by a constructed grounded theory methodology and the chapter sub-headings will outline six conceptual categories: The Feared Anticipated Death, Honouring the Wishes of Deceased, Enabling the AS., Accompanying and Witnessing, Revealing the Death, and Campaigning. Each of these categories will be illustrated with participant quotes describing their experience.

The dynamic interactions between two of these categories - Enabling (Section 5.4) and Campaigning (Section 5.7) - are identified as particularly important roles described and taken on by participants, comprising various activities. As part of the role and activities of Enabling the AS, this category includes the experience of the suppression of feelings, anxiety and isolation, and the processes of stigmatisation and gatekeeping and comes about in relationship with the categories The Feared Anticipated Death and Honouring the Wishes of Deceased.

As part of the role and activities of Campaigner, this category is linked to the experience of opening up and joining, which appears to lessen anxiety and reduce isolation, being linked to activities that challenge the stigma of assisted suicide. These findings suggest that the role of Enabling the AS requires a high degree of stress and distress for the bereaved, that is, for these participants, mitigated by taking on the role and activities of a Campaigner.

5.2. The Feared Anticipated Death

A category emerged that was described by all participants, and related to the painful death that is imagined will occur without AS. This involved descriptions of uncontrollable pain, symptoms or unwelcome dependency and that therefore must be avoided by enabling AS. Participants described both themselves and the person choosing AS as being able to manage their emotions during the process so that they were able to complete the arrangements including the journey to die. However, they also discussed great fear and emotion in relation to the continuing illness and death they (and the person choosing to die by AS) imagined might come about if they did not choose assisted suicide.

This category was strongly linked to the rationale for AS. All participants discussed diagnosis and symptoms as part of their rationale for the decision for AS and usually began to talk about this near the beginning of the interview as part of the narrative of the stages involved in this experience. This rationale is described as shared by the deceased and the bereaved.

"Because she had Mesothelioma, no, it was the most cut and dried reason" - P6E

Participants all described the decision-making process of the person choosing the AS, as being explicable because of the life limiting or debilitating illness.

"When she first got the diagnosis, she decided then that she wanted to end her life and that was it" - P9F

"two years after his accident where he said 'I want to consider Dignitas' and then we spent a year going through the process" - P3C*

[*The accident had led to lower body paralysis.]

All participants shared stories of painful or unbearable deaths as part of their beliefs and thoughts about death and dying. Sometimes these were personal experiences of the deaths of other family members or friends. These expectations of death sometimes derived from hearing about the experience of deaths of other family, friends or acquaintances but were present in all the interviews and appear as examples of a rationale for AS.

Participants also noted the diagnosis of the person choosing AS near to the outset of each of the interviews, so that it set the scene for the rest of the interview discussion. For one participant, discussion of her mother's diagnosis came within two minutes of the start of the interview and followed a description of her fathers.

"my father died in (year) of a neurological- well he had a neurological illness and multiple system atrophy and he died in a nursing home and he died a very drawn out death and I don't say this lightly but he did look like an Auschwitz victim, umm, you know, in the days leading up to his death and I think he'd starved and dehydrated himself to death which was a horrible way to die". P1A

The participant went on to describe an example of someone dying of the same illness as her mother.

"Progressive Supranuclear Palsy. It's very similar to what my father had. It's some degenerative terminal illness which destroys brain cells which control muscle function so

Dudley Moore had it and when he died the only part of his body he could move, the only way he could communicate, was by blinking, so it's a really horrific way to die, because your brain is still fully functioning, you are basically trapped / can be trapped in a useless body." P4D

She then went on to describe how she imagined her mother's death might have taken place if there had not been AS.

"we knew that it would be / could be a very slow long decline and she could be incredibly disabled and suffering horrendously and we would, in turn, suffer watching her suffer and you know you just don't want to see someone you love / it's bad enough my father…" - P4D

All participant interviews include a rationale that makes links between diagnosis, a possible and feared death and the decision for AS. This rationale appears to form part of how these bereaved construct meaning about making the arrangements for AS. This aspect of the experience of being bereaved by AS emerges in the interviews as a strong need for a rationale, and appears to be constructed by the family or friends who are involved in the arrangements and continues on as part of their bereavement.

5.2.1. The compelling decision to support their relative to have AS

In all cases except one, participants described that they feel the deceased person would have gone to seek assisted suicide despite their views.

"he would have gone no matter what. He would have done it. He'd have hung himself in the barn if we hadn't agreed to go with him, you know, he really would have done that." P13I

During one interview the researcher asks the following question "if you'd said we don't want you to die in this way, what do you think she'd have done? To which the participant replies:

"she'd have said well I'm sorry but it's what I want to do. Yes." P5E

One participant related how her relative had tried to take her own life unsuccesfully so that she had felt compelled to find an alternative way to assist her to end her life.

"I don't want her to throw herself under a bus or a train or do something or cut / slash her wrists because she's absolutely determined to die, so I phoned up Dignitas, because I'd heard about it, I think, from her" - P9F

The compelling nature of family love or friendship was often linked closely to the participant's decision to carry out the wishes for AS. This relationship is key to understanding their experience of being bereaved by AS and how they were affected. Their need to enable the AS was sometimes described as being at some cost to themselves both at the time and since, needing them to suppress any mixed feelings they might feel towards the dying person or their choice for assisted suicide.

Occasionally a participant explored the conflict they felt and ambivalence towards the deceased for choosing to die in this way. They expressed how they had little influence on their relative or their decision for assisted suicide.

"she was so determined it was going to happen this way and that way." P11G

The person choosing assisted suicide is described as set on having this kind of death sometimes for both personal and campaigning reasons.

"She did it for everybody, you know, she was determined to do it to make a point really." P10G

Then as the illness progressed much more quickly than expected, the participant discusses how they would like to have cared for her at home with support of Macmillan nurses and the palliative care team, describing how her relative was still determined to go.

"She was desperate to do it, so we had to take her in the car, with all the oxygen and everything, that was just horrendous. So it wasn't our choice to take this dying woman, literally dying, getting worse by the minute and her breathing getting worse and worse. It was horrendous." P10G

Then explained how they had not always wished to travel to Dignitas.

"We didn't want to take her . . . The plan was that she was going to go and we may or may not have gone over to join in the farewell or whatever. However, umm, she got so ill, she couldn't get herself there, she couldn't have got on to an airplane." P11G [they then had to drive to Switzerland]

This participant described being diagnosed after the death, with post-traumatic stress as part of her grief reaction.

"because it was so horrendous, rather than anxiety and depression, she- [her GP diagnosed] *-it was post traumatic stress." P11G*

5.3. Honouring their wishes and the relationship with the deceased

Events were all described as taking place alongside the pre-existing relationship to the deceased and the endeavours involved in trying to carry out their wishes for AS. An understanding of their relationship with the deceased was frequently described as part of the experience of being deceased by AS. Assisting them in carrying out their wishes was important as part of their relationship with this person and is described as a way of honouring them.

"It feels like it's really about how my relationship with him was and if anything the fact that he chose to die is only helpful because he wanted it. He had what he wanted" - P2B

Many of the people choosing assisted suicide were identified as being strong supporters of this way of dying, wanting their deaths to become part of the ongoing campaign. The support of campaigning organisations such as Dignity in Dying (2021) were often mentioned alongside an interest by the media.

"the BBC interviewed us immediately after she'd died, just outside the room, and I think and because my mother was desperate, she was very sort of umm / she was quite an activist in many ways, so she really wanted the law to change, she was also interviewed a week before she went to Dignitas" - P4D

5.3.1. Character of the deceased

The relationship with and character of the deceased person that chose to have assisted suicide is core to all the descriptions of the experience of being bereaved in this way. There appear to be common factors in the descriptions of the person choosing assisted suicide including their anxiety about becoming dependent on others, their independence and their pragmatism. Participants describe being compelled by their love and respect for the deceased to take on what was also discussed as a stressful task.

"She was very pragmatic. She was very pragmatic about life and death and I think she already had sympathies with the voluntary euthanasia society as it was now, now Dignity in Dying" - P5E

Descriptions of the characteristics of the deceased or of their relationship with the deceased were frequent and played a significant part of all the interviews. The following quotations relate to different people who chose assisted suicide.

“She was not demonstrative in any kind of emotional way” - P7E

“She was very ordered in her life. Everything was sorted out.” P10G

“She was a very strong person. She knew what she wanted.” P13I

“Very, very independent. Had always lived on her own you know so she didn't want anyone to go and see her. I did / I did disobey her and go and see her and then, when she was / I mean she was dying for a while, when she was dying, she didn't want anyone to go.” P11G

Some ambivalence appears within some of the descriptions of the character of the deceased and participants discussed how they were not able to easily disagree with their decision for assisted suicide. As this became apparent in the first two interviews, the researcher noted this in Memos and developed a specific interview question to further explore this experience of needing to comply with the decision for assisted suicide. In subsequent interviews this led to findings that became the focused code, ‘the compelling nature of the decision to support the assisted suicide’.

In the following eleven interviews, I asked, *“If you had not agreed* [with the decision for AS] *what would have happened?”* This enabled further exploration of the character of and relationship with the deceased, and how this affected their experience:

“she was / I don't know if you know, she was like a sort of poster girl almost for the campaign.” P4D

“I didn't want her to do it, because we just wanted her to sort of / she'd have got a lot of support if she'd stayed in her flat, umm, she ended up having a different GP towards the end and he was delightful and I know that he'd got a lovely attitude and I'm sure she'd have been comfortable, if you can say it, just dying at home and / she wanted to die in the country that she'd lived in all her life. She didn't want to have to go abroad. But / she didn't just do it for herself” - P8E

Descriptions of the characters of those choosing AS were always part of the interview and were often offered as part of their understanding of the decision for AS.

“There is no way that he would want to be cared for and not be able to do his own thing.” P9F

Many of the descriptions of the deceased show great love, respect and concern for the deceased.

“he was very much a man who lived in the moment and not caught in his illness or mortality even. He never had any fear of death.” P2B

5.4. Enabling the assisted suicide

All participants spent considerable time during the interview describing activities associated with enabling the AS. Participants became involved in arranging many of the practical aspects of the death, including initial contact with the enabling organisation, the application process for agreement by the right to die organisation, the travel arrangements to the assisted suicide and the arrangements for disposal of the body after the assisted suicide. This focus on the administration involved in arranging this death included descriptions located within a chronological story of the events or stages in the process towards the event of the AS. See Fig. 1.

Enabling AS requires many actions taking place across time though the stages making up these arrangements. Participants were usually responsible for most or all these stages depending on the health and capacity of the person choosing AS. This added a high level of endeavour and responsibility to the role of being a person chosen to take on this responsibility and was a key experience discussed by those bereaved by AS. The following sections describe some of the tasks involved in this process.

Most participants discussed the responsibility for arranging travel plans, for example:

"I phoned up and booked this day, umm, and she was much happier then, much happier." P5E

They also reported completing paperwork, and gave descriptions including the amount and complexity of the paperwork involved, which is often largely the responsibility of the participant.

“whether it was in this country, anywhere, because you've still got to go through the paperwork. It's not an easy process.” P3C

The eleven participants that knew in advance about the death, related how they were involved in many complex tasks involved in the practical and beaurocratic arrangements to enable a death by AS. The descriptions of the events that result from having this role in assisting the person choosing a AS include many examples of the intense emotional experience that occur from a death of this kind. Participants describe needing to stay business-like and to control or suppress their grief in order to enable the arrangements to be carried out, including the event of the death. Participants told of the stress or worry they suffered both during and since the death, feeling anxiety, often about aspects of their responsibility for the process of AS.

Their description of the experience of being bereaved in this way involved going back over the events of the arrangements for the AS and making sense of these as part of their grieving process. Their anxiety about any possible suffering that occurred for the deceased person and their ongoing endeavour to identify with and empathise with what they were experiencing is a key feature of what they report.

"*we knew it was going to be that week because it was just the way it was and I kind of said we sort of spoke about it and I was like very – it wasn't even a question for me – for me it was like giving him a great gift being able to release and know that he was out of pain and God it was (cries)." P1A*

"off we went and, as we're sitting flying, he is sitting next to the window and he looked / turned around to me, and he said, umm, just think this is the last time I'll see this view" - P12H

Many of the descriptions of the stages and processes were marked by the participants' endeavours to arrange AS which became the focal point for their care as they moved towards the end of their lives, or in the face of difficulties or worsening symptoms. The responsibility for arranging and making the journey to where the assisted suicide was carried out, frequently appears to have affected participants, causing them to have complex and painful feelings that relate to aspects of responsibility and guilt for "inflicting pain" by accompanying the person to fulfil their wish for AS. This painful duty is seen throughout the participant interviews for those who were involved in the arrangements for the death. For example, one participant described how accompanying his sister to an assisted suicide in Switzerland evoked many feelings for him.

“I was sort of part of it was inflicting pain on somebody else who is / our job was to look after her and part of the looking after her was painful, . . . You don't want to drag your sister out of her beloved flat and take her half way around Europe, in a condition where she shouldn't be travelling half way around Europe.” P10G

All categories indicate that being bereaved in this way leads to the experience of worry and anxiety, inhibition or suppression of these feelings and the experience of emotional and social isolation. Travelling abroad was linked to their experience of anxiety, focused on their concerns about causing pain to the person choosing AS and many of the participants imply that to change the law to let the death occur in the UK would make AS much less stressful for the person travelling abroad to die.

5.4.1. Worry and anxiety

Participants often talked of their raised anxiety about all aspects of the arrangements for assisted suicide with two main areas of concern. This anxiety was closely linked to the conceptual category The Feared Anticipated Death, comprising many coded examples of what was imagined might take place as part of the dying process if the assisted suicide were not arranged. The person choosing AS was always reported as sharing this great anxiety about some form of Feared Anticipated Death.

There was always anxiety expressed in relation to the fear of legal penalty with descriptions of being careful to observe particular safeguards about their role in the arrangements as well as fear of being interviewed by the police. This was frequently associated with their return to the UK after the death and if the police would ‘*take action’* against them or other family members, specifically about their own responsibility for assisting their relative:

“I became a lot more anxious about the implications”. P5E

Some participants were interviewed by the police and this caused them further uncertaintly if they needed to wait to find out the outcome of any legal penalties. This conceptual category is closely linked to the social context including the legal position in the UK and the resulting, often polarised, debates about the legal and ethical framework taking place about AS in the UK.

The compelling need to care for the person choosing AS, both to protect them from pain and to carry out their wishes, imbued their actions to enable the death with great emotional significance but at the time also with a need to be business-like so that they might best enable the arrangements.

5.4.2. Suspension of Feelings including Grief

Participants describe how as the enabler of the death and supporter of the person choosing AS, they were required from early on to suspend their feelings, for example

*"We almost had like business meetings." P6E (*between the person choosing assisted suicide and the participant).

This participant describes how feelings were suspended or delayed for some time after the death.

"holding these letters, you know, so yes, you're wrestling with trying to be competent, business-like, doing what she wants and then realising the enormity of it, umm, but actually I didn't / for a long time I think / honestly until recently I didn't feel anything." P10G

Participants also showed a strong tendency to need to control and avoid feelings including any ambivalence they might feel about both the decision for AS and towards their relative or friend. Feelings were often reported as being suspended before the death by being busy with arrangements, during the journey and up to the time of the death.

"*I knew all the way along that he was going to die and that I would have plenty of time after he died to mourn and to collapse, to do whatever. It was a finite time and I knew I had weeks." P2B*

Participants related that some of those family members or friends who were told about the planned assisted suicide, but were not involved in the arrangements for the AS, found it hard to manage their feelings.

"in some ways I think the few people she did tell she found it quite hard because they'd end up in a sort of sobbing heap at her feet and then you're having to deal with that emotion"- P12I

This is reported by participants as being a further burden for the person choosing AS. Participants report themselves and the person choosing AS needing to avoid this kind of emotion.

5.4.3. Stigma and gatekeeping

Participants expected and sometimes found stigma relating to the choice for AS and experienced the views of others as being either 'for' AS or 'against' AS. They were then involved in gatekeeping information about the planned suicide to avoid their anxiety that the AS might be prevented. It might be expected that for those living in a country without a legal framework for AS there is likely to be stigma associated with this kind of death.

All participants discussed people who do not agree with AS describing their beliefs about these people and their motivations. Choices were made at an early stage about who would be included in the planning or knowledge of the AS. This was often related to how these people might or might not be expected to support the decision. Some participants were highly critical of people who do not agree with AS.

"There's a great fear of death as simple as that. Bottom line no one likes the idea of pain. When you really suffer and it's not about suffering it's about that final fear of letting go and so much that is unresolved. People who are unresolved in themselves" P2B

Sometimes family members who were told were extremely upset about the decision.

"immediately prior to going out he took the decision to tell his parents and his sister. Unfortunately their reaction was *not great and that led him not to tell anybody else, which I think was a shame, umm, but he did write a lot of letters". P12H*

As noted, participants seem to have been likely to suspend or censor some of their emotional reactions during the arrangements for the AS. This appears to have been a way of concentrating on achieving the successful outcome of enabling the AS. Participants also describe their role in gatekeeping the secret plans for the AS and discuss feeling further isolation and inhibition about discussing or sharing their experience of a AS with others in their community.

“because I would have liked to discuss it with someone, well, I couldn't really discuss it with other friends, because they are his friends as well, and he wouldn't want the subject to be brought up” - P13I

This included some people who were considered not to agree with AS because of their professional background.

“I think her motivation for being a specialist in end-of-life was to create the best palliative care . . . she could never see herself in a situation where, umm, she could assist someone to die, as a doctor” - P4D

Participants expressed many concerns about their understanding of the legal position in the UK, and anxiety that they would be interviewed by the police on their return to the UK. The resulting secrecy and perceived risks of legal action imposed an onerous responsibility on them.

“*again you're holding this information and it almost feels as though it's written all over your face.” P6E*

“Everything had to be secret. And you had to be careful what you said. You couldn't say goodbye to anyone, umm, it was all having to get the medical papers.” P3C

This was frequently compared against their experience of the organisations abroad that worked within a different legal and ethical framework. The processes involved were discussed as part of the rationale for AS.

“she went to a solicitor, to make a statement which was signed by her to say that her decision was her decision, she was of sound mind, you know, even if they accompanied her, you know, she tried to put as much protection around it as possible.” P8E

“and then eventually we got the green light for Dignitas, which you probably understand is when it's …… green light which means that you've just / everything on paper is fine.” P4D

“they give you the conditional green light. They want a lot of psychiatric reports. And you’ve got to get all these without knowing why. And then it only goes ahead once you’ve met the Swiss doctor twice. The issue would be had he got mental capacity.” P1A

The perceived need for secrecy within this legal setting impacted greatly on the bereaved and as a result of this apparent need for secrecy many participants reported feeling socially isolated in their grief and alone with their experience of being bereaved by AS.

5.4.4. Gatekeeping information, social isolation and the experience of suspending feelings

As part of the unusual quality of this kind of death, families made very private and often secret arrangements before the death. Those involved in making these arrangements all describe making a sharp distinction between those who knew and were involved in some way, and those who were not told about the decision. The person choosing AS usually decided who would be included in knowing about their plans and this was seen as a private matter for that person that then led to the bereaved becoming part of this secret and often becoming gatekeepers for that secret, adding a further responsibility.

"No. Not a soul, no. He confided only in, umm, his family and his family and one of the neighbours down the road." P12H

"we'd held this a secret and we hadn't talked to them about it." P5E

"very private decision, umm, I told my close friends but not until quite near the time." P9F

This information was seen as an onerous responsibility.

"a bit like knowing someone's on death row." P6E

None of the participants who knew in advance and were involved in arrangements (11) were able to talk to any of their friends and family, but reported having one or two family members to talk to about this. However, discussion with the person choosing AS was limited to protect them from worry.

Participants related that they were required to suppress their feelings to other people both in relation their role as enabler but also as gatekeeper of the secret arrangements. They also reported the need to suppress their feelings, including those related to grief from the deceased and other close family members, while carrying out the tasks required to enable and accompany the deceased. The suspension of feelings was linked with feelings of social and emotional isolation for all of the participants.

"It was horrendous having to creep about getting bits of information and it was very lonely because we can't tell anybody." P1A

"you can't tell people why, and I think that has been the biggest thing, you can't tell anybody, you have to contain it." P5E

"it was very isolating." P4D

All participants described their experience of the social taboo around AS and talked about their understanding of the socio-cultural climate that existed for them at the time of the death and since then.

"At the end of it everyone is grateful but there is still a stigma. And you come back and there is no funeral, no nothing and that is big." P9F

For some of the participants this resulted in anger at the current legal position and at people who are felt not to understand the need for AS, and they may feel highly inhibited as there is a social taboo about suicide and AS.

"because of the laws in this country I didn't want anything to impede what she wanted to do, so I didn't want anyone overhearing, thinking well that's not right, that's not allowed." P11G

One participant reported an extreme feeling of isolation, feeling that no one else could understand them.

"There were very few people I could actually allow to literally touch me..They would look at you and say 'how are you' and you'd say fine..And what you want to say well I actually feel like my skins been ripped off but I actually don't really want to have this conversation with you because I don't know you and you didn't really know him and you are nothing to me so really go away" - P2B

This participants' experience of bereavement is described as being profoundly affected by the choice of death, with a particularly strong and visceral reaction towards those percieved as not understanding them.

5.5. Accompanying and witnessing

5.5.1 The Experience of Time

In all the interviews the description of events took the form of a narrative or story of the events in chronological order. Time forms a significant part of the experience of the bereaved in all the interviews, both in locating the stages of the events, but also in relation to the limited time involved in the unfolding of the illness, symptoms and varying control retained by the person choosing assisted suicide. Time was a significant part of the experience in the interviews, attributed to both the person choosing to die, but also by the participants, and was linked directly to control.

As symptoms worsen there is a limited time left to enable the capacity to travel or have the capacity to choose to die in this way causing the participants a further feeling of being compelled to carry out the wishes of the person choosing AS.

“I remember the nurses saying to her, if you want to do this, you've got to do it quickly and then it was a rush in the end, it was all a rush.” P11G

Participants described how having control when death occurs, rather than to allow time to take its course, was a significant aspect of the decision for AS.

“he made that decision to leave. I don’t know if that make sense to you. It make sense to me. Yea he just left.” P2B

The organisations offering the assisted suicide had a legal and ethical framework that families need to acquaint themselves with and negotiate to get approval for the death. Participants talked about the organisation as having a key role in setting out the tasks and stages that needed to be achieved to die there. All participants talked about being given ‘the green light’ describing when Dignitas or Life Circle approved the request for assisted suicide.

“they are very rigorous – they don’t even give you – well they give you the conditional green light.” P1A

5.5.2. The Timing Of The Assisted Suicide

The experience of this process was affected by time constraints and the ongoing need to consider the timing of the death, both to enable the death to occur as far in the future as possible as well as to happen before the journey was no longer possible. Participants usually described their experience as a chronological account of the stages towards the AS, the reasons and rationale for the timing of the assisted suicide. The rationale for the timing was always linked to worsening symtoms and most described how close to the end of their life many of the participants had become.

"when we eventually went to Switzerland she was / she could just about feed herself because she couldn't hold her, umm, cutlery and she couldn't get it / she couldn't lift her arm far enough to get it to her mouth, so she was just borderline being able to sort of care for herself. I mean she couldn't cook or anything by then but she, you know, she could still shower and go to the bathroom." P10G

"he was already having trouble eating, you know, things / his food was getting stuck in his gullet sometimes. He'd have to cough. He said that's not me. I am not going to sit like that." P2B

For some of the participants they describe how the person choosing an AS might not be so close to the end of their life but that they could not bear continuing with debilitating symptoms, however it might have been some time before death would have occurred without the assisted suicide.

"He couldn't make himself a cup of tea or get himself dressed." P12H

In those cases the decision is linked with the person choosing AS, and their tolerance of being dependent and wishing to end their life at that point.

"He chose the timing. He was the only one who knew what it was like for him and once he had made the decision. Once he had decided he just wanted to get on with it and wanted to go" P13 I

"I couldn't bear to see her like that either and she couldn't bear to be like that and she didn't want to be a sick person. I think it's just she didn't want to be a sick person." P9F

5.5.3. Travelling with the deceased to the AS

Travelling with their relative or friend, was a key part of their experience and this is described in much detail in the interviews.

"the process of getting a tetraplegic, umm, in to a car and then from a car on to a plane, in a plane seat and then off at the other end, in to a taxi and then from the taxi to a hotel and there were no specialist facilities, umm, we stayed in a normal hotel, uhh, so I had him to lift, manoeuvre, etc. which I'd become quite skilled at, but you can imagine somebody who / a grown man, a six foot man, who is a dead weight, uhh, it was physically quite hard, as well as emotionally hard and I think it's a shame that that had to be there." P3C

"It was the painful part, the most painful part, of course, the outcome is always going to be distressing and you know to say the least, horrendous part was the journey and the / having to wait three days [in Switzerland]*, had to be done, but it was really the journey." P1A*

Participants sometimes found themselves travelling alone with their relative or friend to the AS, becoming solely responsible for their physical and emotional care during the journey there, and at the time of death.

"Each step is a painful saying goodbye. Then you arrive and you're disorientated and you're not well and you're taken to a hotel and then you / you shuffle in to the hotel, bottles of oxygen." P6E

"And I was the one who dealt with her incontinence and everything, not feeling sorry for myself about that, I'm just thinking I felt very very responsible and I couldn't sleep properly and every time she kind of stirred I'd think oh is that it, is she going, you know." P11G

For others in small groups, one participant would often find themselves taking on this role as a result of their family relationship to the person choosing AS, for example, as a woman to her sister.

Only one participant described a more positive experience before the death.

"I know it sounds absolutely crazy, but it was actually a surreal holiday, the five of us had a wonderful time, until he died. We went out. We laughed. We had lunches and you know we went out, we walked, he was in a wheelchair by then, we walked him along the lakes in Z.,

umm, we had a really good last holiday and umm / and he was so, so, glad and happy that we had all supported him in his final days." P1A

This participant experienced being well supported, travelling with a group of three other family members as well as the person choosing AS, spending a couple of days there before the death, and were unusual in staying afterwards for the cremation rather than flying home the day afterwards.

5.5.4. The Death

Participants also found the experience could be surreal or strange, often reporting a lack of feeling as they struggled to manage the arrangements and the needs of the dying person.

"when I went with her for the green light, such a surreal experience." P5E

"it became very surreal, at this time yes, everything was sort of a bit sort of heightened and a bit unreal." P1A

Their description of the place where the death occurred was usually described in some factual detail as participants have a very clear recall of the experience of the death and the place the death occurs. They also all describe a strong wish that the death had been able to take place at home in their own surroundings.

"it was very functional and they did a perfectly good job. It's umm / it's a bit of a dying factory and which is unfortunate, again, I come back to the whole point, you should be able to be in your home, shouldn't have to go to a place where they you know go to a dying factory". P10G

5.6. Returning to the UK and revealing the death

Before the death participants (and the deceased) made a strong distinction between the people who were expected to agree with this decision and those who did not agree, and, as a result, about those who would be told and those who would not before the death took place. On returning to the UK participants discussed their role in communication with friends and family who had not been aware of the decision for the AS, or subsequent death. They were therefore responsible for both informing others about the death and also the circumstances of the death. This was described by two participants as being an onerous responsibility. For example,

"*and when we got back they just wouldn't stop contacting us…we felt that we had to keep re telling what happened over and over again…." - P6E*

Three participants discussed the experience of being in contact with the media following the death.

"It was very cathartic actually and also I found it quite empowering and when my mother had died, my main sense, particularly from / you know you realise it was just headline news, was a sense of euphoria" - P4D

Participants described how they usually returned to the UK within the next day or so. All except one family left the body behind, not staying for a funeral but arranging for the ashes to be returned home after cremation. Only one participant described the family staying for some days so that they were present for the cremation, which was described as being a rewarding experience.

Six participants described how there was anxiety on return in case of investigation and legal action, with four participants describing police involvement.

"Although somebody did shop us to / well I say shop us, but someone did contact the police and ask them to investigate." P5E

For all of the other participants, a memorial took place back in the UK at a later date to celebrate the person that had died and this was spoken of as extremely important and consoling afterwards.

"*there wasn't a funeral, umm, but she did have his ashes flown home and we had a memorial and we / (laughs) / it's very unusual / we sent him in to the sky with a rocket" - P13I*

5.7. Campaigning

Participants made frequent reference to the current legal framework within the UK, and this appears to have been an important influence on their experience of enabling a death of this kind. They all report having expectations of being penalised and judged about their decision, experiencing being on one side of a polarised debate, leading them to expect other people as belonging to either camp.

"I do not understand why (the law was was not changed)....it's for political reasons….There are a group of people that think it is abhorrent." P12H

They describe how the polarisation of the debate at the time of the arrangements affected their role as gatekeeper of the secret arrangements, influencing their own hesitance to share their feelings with others, and, as described in Section 5.4.4., they experience social isolation.

Participants include many statements within the interviews that justify the death and decision they made and often gave a rationale for supporting assisted suicide that included ethical issues relating to the specific example of the death they had experienced.

"the gentleman was 104 . . . don't enjoy this life any more, umm, is going to make a statement, uhh, live authentically, autonomously . . . if people had access to a suicide pill, or whatever term you wish to use, from a local chemist, I suspect that gentleman would have actually brought his family around and taken it" - P7E

"I think really if you've had enough umm / if you've really made up your mind and if you've got / all your marbles, if it is your choice, you should be able to do what you want to do yes, but that is my view."

The desire to support a change in the law in support of AS in the UK was mentioned as a motivation in being interviewed by all participants.

"it is something that I feel, on a personal basis / I mean Dignity in Dying actually would have probably liked had I do a little bit more, but we just said / we did our bit, that's how we are." P3C

Only one participant described themselves as not being a campaigner although still strongly supported the views.

"it's something I've / I find it quite inconceivable that anybody would come to any other decision, that somebody's dying of pain in the corner, that you're not putting them out of their pain . . . As I say we are not campaigners" - P8E

Those who were the most committed described taking part in other activities involved with supporting the campaigning organisation, Dignity in Dying or one other local campaigning organisation, were also those who had been involved in enabling the arrangements for the assisted suicide.

"but it was sort of sense of achievement, it was like you know something positive is going to come from her death and I think because so much publicity was generated and that Boris Johnson wrote in The Telegraph saying, you know, as a result of watching / seeing my mother in the news, he'd changed his view on it, and things like that just made you think, yes, good and she would have been pleased. She would have been proud, this is the kind of person she was . . ." - P4D

Becoming a campaigner was mentioned as being an important part of their lives since the death forming a significant part of their sense of self, forming part of the way in which they honoured the deceased.

"I felt, umm, that [the choice for assisted suicide] *confirmed my view really but you know my father's dignity, who was always in control of everything that was moving really, was denied that in his death. . . . because obviously we're keen on changing the law about assisted dying." P1A*

The belief in having the choice to end their own lives was also something they felt formed part of how they understand their own mortality and forming part of the meaning they have made of the death of their loved one.

"*massive loss of dignity, because this / you know this was / two months before / a month before a vibrant person is now shuffling, can't breathe properly, shouldn't be the case, just to be able to say I want to die tomorrow." P6E*

5.8. Discussion of Findings

The development of a theory grounded of the experience of those bereaved by assisted suicide, from the findings in this thesis, will be fully explored in Chapter 7: Discussion, following and including discussion of the critical interpretative synthesis of the experience of suicide bereavement. This section will review and discuss the findings giving precedence to two overriding categories and how these might influence and affect the participants, offering further insight into categories, experiences, and accompanying processes for those bereaved by assisted suicide.

The findings suggest that for participants living in a country without a legal framework for assisted suicide there is heightened anxiety leading to a challenging emotional experience for these bereaved. Firstly, they are anxious that the chosen death may be prevented from taking place, thus not honouring the wishes of the deceased, and secondly that the feared and anticipated death will then take place. This Feared Anticipated Death is the powerful driver that overcomes all the other difficult experiences. The anticipated death can include earlier experiences of other deaths and is linked to beliefs about diagnosis.

The interviews show a dynamic interplay between stigma and the experience of isolation associated with the role of gatekeeping. The relationship between secrecy and stigma leads to the necessity to become involved in the role of gatekeeping and causes the bereaved to experience further distress as part of their involvement in enabling the assisted suicide. However, without the opportunity to share this, (depending on their beliefs of how others view assisted suicide), this is likely to lead them to experience isolation.

Following the death due to AS, these bereaved are drawn to campaigning and that there is a positive relationship with campaigning, offering opportunities to share what has previously been kept secret and alleviate the distress of enabling, and to challenge any stigma they might experience due to their involvement in the AS.

5.8.1. Cultural and religious influences

During the interviews participants were given the opportunity to share their spiritual, philosophical or religious beliefs in response to a question asked towards the end of the interview: *Can you tell me how this experience has affected your spiritual, philosophical or religious beliefs?* All thirteen of the participants used this as an opportunity to reflect on their own beliefs in relation to assisted dying. For example, three stating that they had not changed their own views and would probably not request an assisted death. The remaining all discussed the circumstances that might lead them to consider this alternative although all linked this to circumstances, specifically what illness they might be suffering from with three mentioning dementia as a good reason they might want an assisted death. For one of the participants who was not involved in the arrangements for the assisted death, he had now decided that he would investigate how to take this option in the future.

The meaning making that had taken place since the death was largely confined to their strong commitment to the right for people to be able to choose how to end their lives and participants did not mention having a strong spiritual, philosophical or religious framework that related to or was challenged by this commitment. Participants were not asked to describe their religious background information, however their ethnic background was invited with eleven participants describing themselves as White British and two as White European.

A small questionnaire-based study by Pentaris and Jacobs, (2022) asking participants about their support for the legalisation of assisted dying in the UK, suggests that ethnicity and religion may be linked to these views. Those participants who identified as having a faith were less likely to support assisted dying. Those participants that identified as having no religion were much more likely to disagree with a change to enable assisted dying, with 53.8% of Muslims, 39.7% of Christians, and only 9.9% of those who described themselves as having no faith.

Only three female participants within this study chose to take up the question directly and discuss their own spiritual, philosophical or religious beliefs. Of these one talked directly of being different to her father who did not believe at all in any afterlife, however although she did not have a specific religious belief, felt that there might be something afterwards. The remaining two also felt that they could not believe that everything ended at death and talked of feeling that their relatives were somewhere. For my participants this hope for an afterlife was not linked to their support for assisted dying, however it is notable that only one participant was definite about choosing this death for themselves with others being very specific about when they might consider this.

5.8.2 The challenging emotional experience of enabling assisted suicide

As participants related in retrospect, their experience of the events involved in becoming bereaved by AS, they used words describing many of these experiences in negative terms, for example the following words were used frequently across all the interviews: *awful; bad; difficult; hard; scary*. The emotional consequences of taking on this responsibility were always included in the descriptions of the processes, indicating the intensity of the effect on the experience of the bereaved.

It emerged during analysis of the interviews, that these negative emotional experiences have a strong relationship to the three other categories that have emerged from the data analysis: 1. The Feared and Anticipated Death; 2. Honouring the Wishes of the Deceased; and 3. Enabling the AS. The emotional experience of being bereaved was affected profoundly in all cases by the circumstances of the AS, particularly in relation to their role in enabling the assisted suicide taking place within the social and legal context of a highly polarized debate about assisted deaths.

All participants expressed negative beliefs about what their family member might experience by continuing to live with or by dying as a result of their diagnosis, if they had not undertaken to have AS. This Feared Anticipated Death was always shared by the person choosing assisted suicide and compelled them to protect their relative against this feared outcome. The Feared Anticipated Death was also part of their rationale for supporting their relative, and subsequently their belief in the right for others to have AS. The most significant person discussed by participants during the interviews was the relative or friend that had chosen to have AS.

Their experience of bereavement also seems to have been strongly affected by the quality of their relationship with the deceased. Within this category, identified as Relationship with the Deceased, are codes showing similarities in their experience of having a close relationship with someone who chooses to die in this way, for example the focused code, the Character of the Deceased.

A constructed grounded theory approach is used to explain how the interaction between these categories creates a powerful dynamic affecting the experience of people bereaved in this way.

5.8.2. Campaigning to alleviate the distress of enabling

Having been an enabler of the assisted suicide involved a great responsibility for actions involved in arranging the death (including accompanying them on this difficult journey through the arrangements and the journey abroad). This has emotional conflict within it as the bereaved felt both the need to end the pain of the deceased and give them their wish for assisted suicide, but also did not wish them not to die, often fearing that the journey caused pain for the deceased.

During the arrangements for the AS the bereaved needed to suspend feelings and be business-like to carry out the actions required, however this had a negative dynamic relationship with the need to get support by telling others in order to reduce the experience of isolation. Upon the relief following the successful completion of the AS, and the fulfilment of honouring the wishes of the deceased, the bereaved find a positive dynamic relationship between becoming a campaigner and getting support from others by engaging with public discussion and debate about the legalisation of AS. See Figure 1. where there are relationships between Anxiety and Lessening of Anxiety; between Isolation and Joining; between Opening Up rather than Suspension of Feelings and Gatekeeping; between suffering from or Challenging the Stigma associated with assisted suicide. The theory developed from this grounded study suggests that these participants sought to become involved in campaigning, Joining a Campaign, to manage and limit their anxiety and isolation, and that this new role as Campaigner alleviates the distress of Enabling AS.

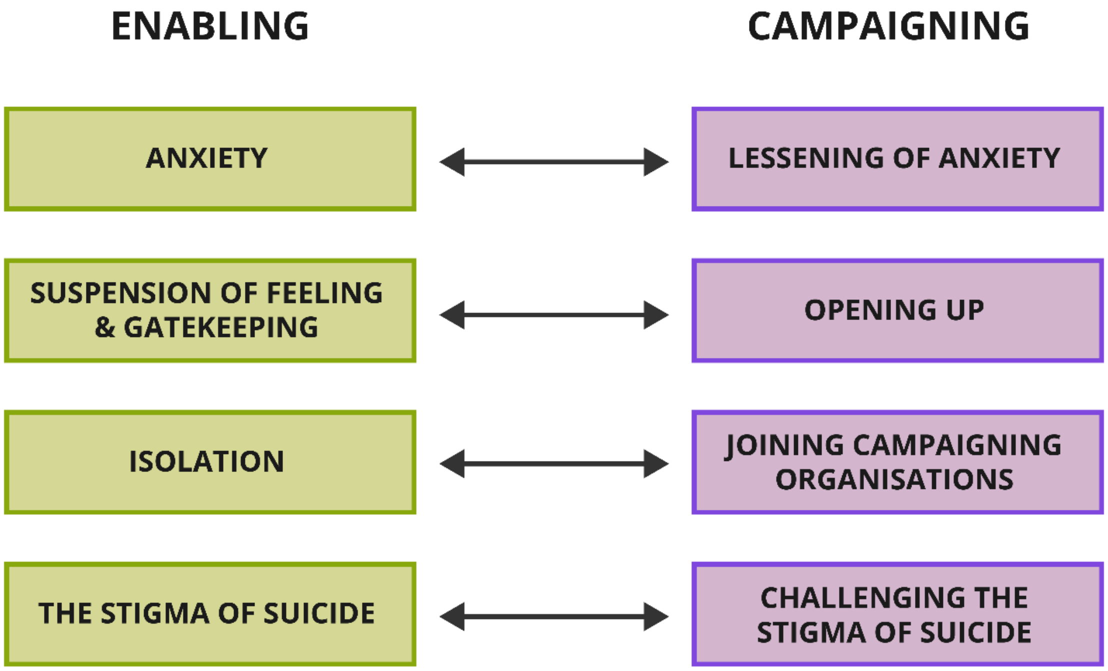


Figure 2. Campaigning to alleviate the distress of the role of enabling assisted suicide

5.9. Conclusion

These findings give insight into the experiences, roles and actions taken by the bereaved within the process of enabling AS. They describe some of the actions and roles for those bereaved by AS that takes place in another country. The findings reflect the current legal and socio-cultural setting for AS in the UK, a country without a clear legal framework, and consider how this affects the bereaved.

The findings have enabled the development of a constructed grounded theory of the experience of those bereaved in the UK following AS and find a dynamic relationship between the roles of Enabler of assisted suicide and Campaigner for assisted suicide.

There is additional opportunity to develop this theory with the findings from the systematic literature review of the experience of people bereaved by suicide (not AS). See Literature Review, Chapter 6. and to discuss how this wider field of research gives additional insight into the experience of those bereaved by AS. See Discussion Chapter 7.

Chapter 6. Literature Review

6.1. Introduction

This literature review forms part of a wider study addressing the experiences of those bereaved by AS in the UK. An earlier systematic literature review (Gamondi et al., 2019b) explored family members' experiences of assisted dying in jurisdictions where a legal framework permits its use but does not include the experience of those in the UK and indeed no other reviews were found which focused on this topic.

Suicide, sometimes described as self-suicide, or self-death, (Gerson et al., 2019) describes an individuals' actions that directly ends their life, with actions taken to carry out a self-suicide or attempted suicide not being illegal in the UK since legislation under the Suicide Act (UK Government, 1961). There is currently no clear legal framework for an assisted death in the UK, although there is limited legal guidance (Crown Prosecution Service, 2021) about the position of those close to a person that chooses an AS and travels abroad for this if they take part in or accompany that person to the assisted death (UK Government, 1961). The experience of those bereaved by suicide within this literature review can offer further understanding and supports exploration of the experience of those bereaved by AS in the UK.

6.2. Literature review question

The review question is: What are the emotional experiences of, and roles taken by, caregivers bereaved by suicide?

The term 'suicide survivor' (Cerel, 2014) has been used to recognise the demanding and stressful issues present in the aftermath of suicide bereavement. The findings from the interviews have shown that those bereaved by an AS also experience heightened emotional distress and anxiety. Whilst the experience of being bereaved by AS will differ from the experience of being bereaved by suicide, there may be similarities and the opportunity to study the wider research of those bereaved by suicide can build on the findings, consider the different qualities of this experience, and enhance the development of theory. Conducting a literature review to focus on studies about the experience of carers, usually family members bereaved by a suicide, will allow further exploration of the differences as well as similarities for families when someone they care for chooses to end their life with AS.

Being bereaved by suicide has been identified as leading to particular and different experiences of grief (Hanschmidt et al., 2016) with an increased risk of complicated grief and suicide (Hamdan et al., 2020). Studies identifying issues that might lead to risks to physical or mental health for those bereaved by AS have less-clear outcomes. Cerel et al. (2014) suggested that those exposed to suicide are at increased risk of developing post-traumatic stress disorder and the 'continuum' of levels of impact on those left behind by suicide, which ranges from those exposed to suicide, for example as professionals, to those "who are bereaved by suicide in the short- or long-term, as a function of their loss of a close emotional attachment through this tragic form of loss" (Cerel, p. 591, 2014).

Studies that use quantitative methods to research those bereaved by suicide were included in prior reading in preparation for this literature review, however they were found to offer nothing that could be usefully explored in relation to the literature review question. For example, studies that measure the occurrence of complicated grief following the death. This thesis considers the experience of those bereaved, so included studies will use a qualitative methodology.

6.3. Methods

6.3.1. Aim

The aim of the review of the literature was to explore and determine what is known about the experience of those bereaved by suicide, including their emotional experiences. A critical interpretive synthesis (CIS) was chosen as it allows the development of a clearer understanding of experience and encompasses the theoretical generation that this grounded theory study hopes to offer (Dixon-Woods et al., 2006). This review aims to offer an overview of the experiences of bereaved people using evidence-based practice to understand both their needs and preferences (Pearson et al., 2005).

6.3.2. Review Design

Critical interpretive synthesis emphasises the critical relevance of each paper towards the review question and has the capacity to give this higher significance than the critical quality of a paper. Papers have been included if their relevance is thought to outweigh some of the concerns about quality, for example if the content of the paper can potentially inform the aim of the literature review question and the intention of the thesis research question. Whilst critical interpretive synthesis review approaches can include quantitative papers (Dixon-Woods, 2007), in this review they were excluded as the review question addresses the subjective experience of the bereaved.

All the research articles are brought together and analysed using critical interpretive synthesis. The intention of this review is interpretive, rather than aggregative, and using critical interpretive synthesis best accommodates the research question. This interpretive stance is valued for its capacity to focus on generating theory using a reflexive and iterative approach and is congruent with a constructivist epistemology, allowing for multiple and contextual interpretations (Drisko, 2020). Critical interpretive synthesis fulfils the requirement to interpret from findings from a range of studies into a combined finding with the opportunity to identify common concepts and categories (Dixon-Woods et al., 2006), being methodologically sensitive to the constructed grounded theory research methodology used throughout this study (Charmaz, 2014).

The constant comparison required as part of constructed grounded theory (Charmaz, 2014) was used when analysing the conceptual themes appearing from the included research studies. Critical interpretive synthesis considers how the literature defines its problems and the assumptions drawn in the literature and has the capacity to search for both confirming and disconfirming cases (Dixon-Woods et al., 2006). There was potential for bias throughout by over-representing one study over another, requiring the reviewer to pay close attention to reflexivity during the synthesis and attention to any articles that became over-represented in the discussion.

A critical interpretive stance seeks to highlight key concepts and findings, offering a methodologically sound approach to the synthesis. These common concepts are useful in indicating significant links to pre-existing models of grief and bereavement, the adjustment to change or trauma and the impact of social context on individual experiences, giving further weight to the findings and the capacity to create new knowledge (Drisko, 2020). See Figure 2.

6.4. Search Process

6.4.1. Database Searches

Studies on the effect on or experience of those bereaved by suicide can be found in several academic domains, indicating the need to use a variety of databases. Each search was carried out separately in MedLine, CINAHL, and PsychINFO, using EBSCO to collate material and to check for duplication. The search was comprehensive, giving breadth rather than being exhaustive and remaining closely focused on the review question, which, for example, excluded quantitative data when not concerned with the experience of participants.

Hand searching was also used to identify additional studies from six key journals (Crisis, The Journal of Crisis Intervention and Suicide Prevention; Suicide and Life-Threatening Behavior [SLTB]; Archives of Suicide Research; and Suicidology Online, Death Studies and Omega Journal of Death and Dying), identifying eleven studies. A comprehensive search strategy was developed that includes descriptions of all activities (Barnett-Page & Thomas, 2009).

6.4.2. Database Search Terms

The wide field of study included within suicide research requires a careful focus to meet the requirements of the literature review question. Table 5 outlines key search terms used.

Table 5. Database: Key Search Terms

AND	bereavement AND suicide AND (Experience* or perception* or attitude* or view* or opinion* or feeling* or attitude* or perspective* or reflection* or lived experience*)
Dates	1990 – March 2021
Database	Each search was carried out separately in MedLine, CINAHL, PsycINFO, using EBSCO to collate material and to check for duplication.

6.4.3. Selection Criteria

21 research papers were identified to be included in the comprehensive literature search. See below for a record of the search strategy using STARLITE (Booth, 2006), an aid to searching that offers a suitable precursor to using critical interpretive synthesis (Dixon-Woods et al, 2006 and Dixon-Woods, 2007).

Table 6. Selection Criteria using STARLITE (Booth, 2006).

S – Sampling	Comprehensive – Attempting to include all studies relating to research question. What are the emotional experiences of, and roles taken by caregivers bereaved by suicide? Purposive – excluding all studies that fall outside the area of interest – the experience of those bereaved by suicide. Not to include suicide due to physician-assisted suicide, hastened death or euthanasia as the aim of this literature review is to look at a wider field of literature and the possible differences between PAS and suicide. Selective – close attention paid to limiters to exclude literature that is not relevant.
T – Type of Studies	Qualitative methodologies.

A – Approaches	Academic journals, not Dissertations, Books or Magazines because of wish to include research-based writing.
R – Range of Years	Date Range 1990 – MARCH 2021. Literature supporting study of suicide has a longer history than the more limited history of physician-assisted suicide and bereavement. The date range was kept open. The earliest document was 1933 but this was not research. Initial searches included a literature review from 1984 which was used to scope for earlier research. Research from a qualitative perspective appeared from 1980.
L – Limits	LIMITERS HUMAN, ENGLISH, Age – Adult Only. Removed infants, children, adolescents, teenagers. METHODOLOGY – Qualitative Only – Removed Quantitative. CLASSIFICATION – Removed classroom dynamics, military psychology, schizophrenia & psychotic states and behaviour disorders & anti-social behaviour. POPULATION – removed in-patient in acute or mental health setting.
I – Inclusion and Exclusions	What is within the scope, and what is not. The initial search used some exclusions within the search terms used to focus. See Table Search Terms above. Further reading of abstract to enable further clarity and focus on the experience of those bereaved by suicide. Removed the following: See next section for full inclusion and exclusion criteria.
E – Electronic Sources	EBSCO USING CINAHL, Medline Complete, APA PsycInfo. Deleting research that appears in duplicate.

The initial inclusion and exclusion criteria helped to identify the papers chosen.

6.4.4. Inclusion and exclusion criteria

Table 7. Inclusion Criteria

Inclusion criteria	Rationale
Qualitative, interview-based studies about caregiver experience or reviews of interview-based qualitative studies.	Meeting the aims of the review question seeking to explore the experience of the bereaved.

Responses sought from people who were relatives or close friends with the person who has died due to suicide.	Review seeks participants whose relationship was close enough to the deceased to have personal, experiential impact such as close friends, carers or family members. Informed by 'continuum' of impact (Cerel, 2016).
Death(s) due to suicide.	Suicide is identified in the review question.
Published in English.	Researcher has not got capacity to translate.
Studies taken place in Europe, North America, Australia, New Zealand and reported in English.	Population in thesis is from western culture.
Research published in peer-reviewed journals.	Maintaining quality.
Where full text is available.	Maintaining thoroughness of inclusion criteria and analysis.

This review includes research that considers factors that affect grief outcomes for adults bereaved by suicide, such as the experience of distress. For example, the inner world of those bereaved by suicide is explored qualitatively to understand how family members deal with their grief (Fielden, 2003). This review will only include studies that research the experience of grief and will not include studies that use diagnostic or professional objective measures such as complicated grief in the analysis.

Table 8. Exclusion Criteria

Exclusion criteria	Rationale
Quantitative studies.	Meeting the aims of the review question seeking to explore the experience of the bereaved.
PAS PAD MAiD Euthanasia or Hastened Death.	The review question seeks to explore the experience of those bereaved by suicide not those bereaved by an assisted suicide as recently reviewed (Gamondi, et al., 2019). See Chapter 7 - Discussion.
Medical staff/healthcare provider/nurse paramedic or doctor (experiences of).	Review question is concerned with those bereaved where the impact of the loss is felt due to the closeness of personal relationship.
Participants that are suicidal or have Mental	The review question is exploring the experience of the general population of bereaved people and does not seek

Health Disorders or Addiction.	to look at the specific needs of those with specific mental health diagnosis.
Participants were under age of 18.	Childrens experience of grief requires specific focus of research not within this review question and thesis.
Suicide Prevention, Intervention or Reduction.	Not within review question as concerned with the avoidance of suicide rather than the experience of the bereaved.
Military or Veteran Suicide.	These participants require separate and special consideration in relation experience of war/combat and to trauma.
Case reports; personal essays.	Review aims are to synthesise research studies of experience gained using research, not case study or other descriptive writing.
Information created in the media.	Review aims are to synthesise research studies of experience not secondary accounts.
Studies linked experience of bereavement to specific cultural groups.	Review aims to look at literature with relevance to thesis question set in western culture and of relevance for UK bereaved.

To aid this protocol the review excludes literature that defines terms in relation to deaths following ‘assisted dying’. It also excludes papers and writing about legal terms and the legal or political issues relating to suicide. In addition, this review excludes those relating to how current social or medico-legal and political issues may affect the experience or roles of the bereaved. Social context might only appear in studies when the focus of the research is how social factors are experienced by the bereaved, for example the experience of a coroners’ court (Biddle, 2003; Spillane et al., 2019).

Studies that consider quantitative evidence including mixed methods studies, for example that might measure increased levels of complicated or prolonged grief following a suicide, are not included because the review question is concerned with the experience of participants, rather than any professional objective measure such as complicated grief.

The study excludes the effect on children and only includes adult participants. The study will exclude the loss of a child through suicide as there is evidence to suggest that the effect of the death of a child under 18 at the time of their death, merits a specific area of study which is outside the remit of this review (Stroebe et al., 2003).

There is an extensive body of research concerned with wide ranging aspects of suicide including risk, links to mental health conditions, and to suicide prevention. The wide therapeutic literature concerning how death by suicide might be avoided and the clinical experience and responsibility of those in caring professions has been excluded. This research is usually concerned with risk assessment including suicide risk assessment as families who have experienced a bereavement due to suicide are seen to be at greater risk of contemplating suicide themselves (Jordan, 2001) and of experiencing complicated grief reactions (Mitchell et al., 2004).

A further area of bereavement research explores the kinds of support that families have needed and benefitted from so far (Stroebe et al., 2013; Wimpenny and Costello, 2012). This review will include studies that explore the experience of being supported by others, rather than exploring the wider literature that considers the relative success of different kinds of therapeutic intervention. For example, this review would not include measures of the success of bereavement groups or bereavement counselling unless they also included the experience of bereavement due to suicide. The review will not include literature that primarily discusses definitions or terms or the legal or ethical position of deaths in any of the countries that have been enabling suicide or assisted suicide.

6.5. Data Extraction and Assessment of Quality

The Hawker Quality Assessment tool was used to address quality and produce an overall score for each study, ranging from between nine and 36. Hawker et al. (2002) do not provide guidance regarding when a score is too low to be acceptable for inclusion, leaving the determination up to the reviewer. Using the Hawker tool (2002) a score of 19 has been chosen as the lowest acceptable score for inclusion. Previous applications of the scoring tool have also utilised a score of 19 as an inclusion cut-off (Tong et al., 2012). Six were removed.

The search strategy was applied to identify papers and once identified the papers were assessed for whether they met inclusion criteria. This process considered studies that seem borderline, and decisions were recorded. Further limiters and screening were used to further define the database searches including quality control and the Hawker tool (Hawker et al. 2002) was used to further assess methodological quality. A rigorous approach to reporting results was followed, including using a PRISMA flow chart and a table to highlight the findings of studies and synthesise the outcome (Dixon-Woods et al., 2006).

6.6. Data analysis using critical interpretive synthesis

All articles presented a description of the qualitative methodology used including thematic analysis (4), grounded theory (5), narrative (6) and interpretative approaches including interpretative phenomenological analysis (6). This wider range of qualitative methodologies offers a depth and richness, allowing a balance between the strengths of each to offer different qualities to the review.

Critical interpretive synthesis is able to offer a coherent theoretical framework and synthesising argument in the form of comprising of constructs and the relationship between them (Dixon-Woods et al., 2006). The papers were read closely, to familiarise, with first order constructs (for example, quotes from the research) and second order (for example, research interpretations) being identified. These constructs were matched against each other using a constant comparison approach, developing third order or synthetic constructs, allowing any contradictions or flaws in the evidence to be considered as part of a refutational synthesis. See Figure 4 Stages of critical interpretative synthesis. The synthetic construct was grounded in evidence from the literature review and is my interpretation of the evidence, using ongoing reflexivity demonstrated through memo writing and discussion with supervisors to monitor my position and perceptions. A data extraction table was created that records the outcomes. See Table 10.

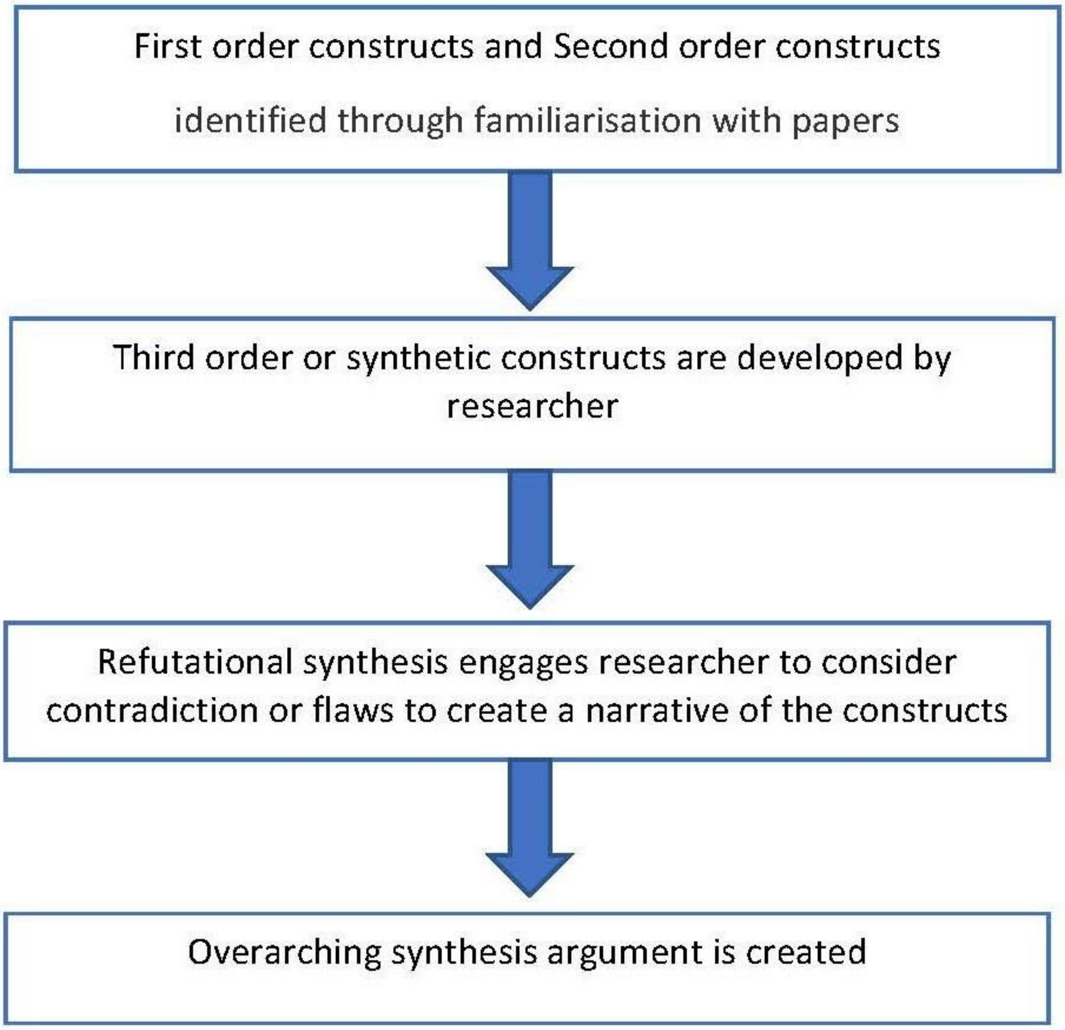


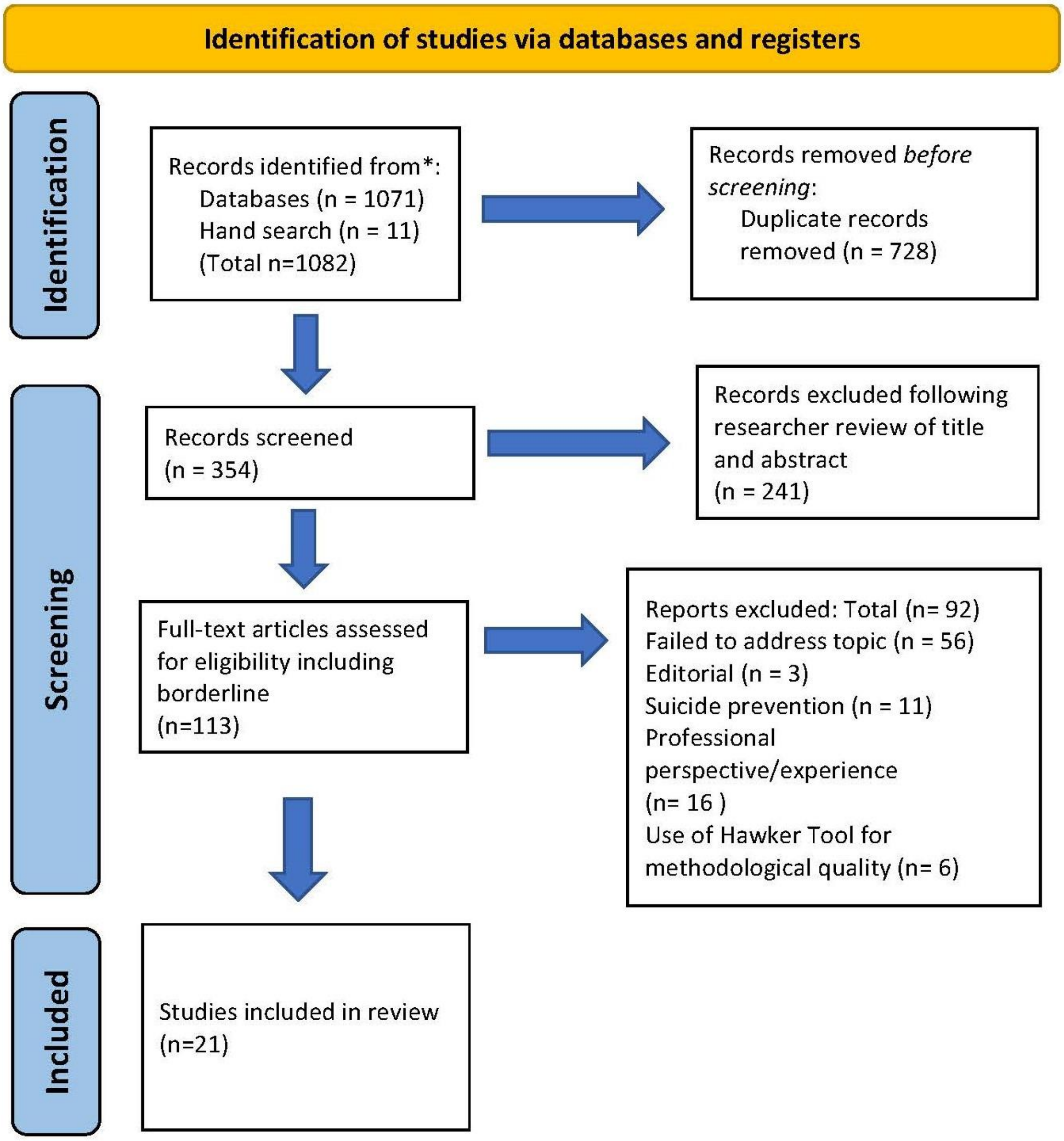
Figure 3. Adapted from Drisko (2020) Stages of critical interpretative synthesis

6.7. Results and overview

A total of 21 articles met the inclusion criteria and are included in the synthesis. All the research uses a qualitative methodology and method. The publication dates of the research studies ranged from 1991 (Van Dongen, 1991) to the most recent in 2019 (Azorina et al., 2019; Hunt et al., 2019; Spillane et al., 2019). Of the 21 studies, four are from the UK, eight from the USA, 5 from Australia, 2 from Canada and 1 from Switzerland.

Table 9. PRISMA flow chart (Page, 2021)

What are the particular emotional experiences of, and roles taken by caregivers bereaved by suicide?



Detail of Studies included in the Suicide Literature Review Question:

What are the emotional experiences of, and roles taken by caregivers bereaved by suicide?

Table 10. Data extraction and study quality ordered by year of publication

	Author (year) country	Study Aim	Method	First and second order constructs	Third order constructs	Hawker Tool Score
1	Azorina, et al. (2019) UK	To explore the impact of suicide bereavement on the interpersonal relationships of young adults in the UK people bereaved by suicide.	Thematic analysis (n = 416). UK young adults (aged 18–40) mean age of 20. Sample of people bereaved by sudden death—the University College London (UCL) Bereavement Study. Free-text responses from 499 adults using an online survey to collect qualitative data.	Themes describing the changes in relationships following the suicide: Social discomfort over the death (stigma and taboo; painfulness for self or others to discuss; socially prescribed grief reactions). Social withdrawal (loss of social confidence; withdrawal as a coping mechanism). Attachments influenced by fear of further losses (overprotectiveness towards others, avoiding attachments as protective). Findings contribute to understanding deficits in support and pathways to suicidality after suicide bereavement. Such disrupted attachments add to the burden of grief and could be addressed by public education on how to support those bereaved by suicide. Shared bereavement experience, creating closeness and avoidance.	The intensity of grief and trauma. Social experience and stigma. Meaning-making.	30

2	Barlow C & Coleman, H (2003) Canada	Exploring how families use social support after a suicide.	Using interpretative phenomenology framework. Participants were interviewed using a semi-structured interview schedule. (n = 6)	Experiences of post-traumatic growth were found for adults bereaved by suicide. Positive growth (‘‘life view,’’ ‘‘knowledge of self,’’ and ‘‘relation to others’’). Suicide survivors gain extra insights due to their experiences but are reluctant to acknowledge that they do. Findings were described within an over-arching theme of time. Social context: ‘‘gaze of others,’’ ‘‘public guise,’’ and ‘‘solace of other survivors’’. “Healing alliances created within and outside the family sustained its members as they engaged in the painful process of personal re-definition and family transformation”.	The intensity of grief and trauma. Social experience and stigma. Meaning-making. Post-traumatic growth and identity.	30
3	Biddle, L (2003) UK	Exploratory study of the effect of coroners' procedures on those bereaved by suicide.	Thematic analysis to identify recurrent problems and their effects. (n = 16) Individuals bereaved by suicide various UK regions.	Experience exacerbates common grief reactions associated with bereavement by suicide, such as shame, guilt and anger; and, by interfering with necessary grief work, most notably, the task of arriving at a meaningful and acceptable account of the death.	The intensity of grief and trauma. Social experience and stigma. Meaning-making including making sense of events of the death.	31

			Recruited via two national organisations (Cruse) SOBS (Support after Bereaved by Suicide). Exploring experiences of the coroner’s inquest.	Lack of preparation and communication prior to the event. Adverse experience affecting resolution of grief. Within courtroom there is shame and stigma particularly with media presence and linked to Coroners’ questioning technique. Relieving relatives of the witness role. Coroners were able to relieve relatives who have given statements from public formal questioning/giving evidence under oath.		
4	Chapple, A., Ziebland, S., & Hawton, K. (2015) UK	Exploring perceptions of those bereaved by suicide or other traumatic death.	Interpretative thematic analysis to consider whether the ‘death taboo’ is evident in these bereavement narratives. (n = 80) UK people bereaved due to suicide, or other traumatic death maximum	Shock and suddenness of the death is tied up both with the circumstances of the death (suicide, murder, accident, terrorism) and the social consequences. Feelings of shame, blame and guilt and attendant negative consequences for the social acceptance of public displays of mourning.	The intensity of grief and trauma. Social experience and stigma.	31

			variation, diverse samples.			
5	D. Dolores Angela Castelli (2013) Switzerland	Understanding and Supporting Survivors of Suicide.	Grounded theory analysis of in-depth interviews using a theme guide. (n = 48) Survivors of suicide of a loved one.	Sense-making: seeking comprehensibility. Reconstructing the process which led to suicide. Reconstructing the figure of the suicide completer. The ending of the quest for sense. Memory-building: dealing with the legacy. The meaning-making continuum: identifying four kinds of meaning-making. One relates to social context: Suicide becomes the driving force behind a commitment to prevention of suicide. The remaining three are in relation to individual sense making: The source of an increased awareness of life. No constructive personal existential meaning, which prevents the rebuilding of self.	The intensity of grief and trauma. Social experience and stigma. Meaning-making, including making sense of events of the death. Post-traumatic growth and identity.	30

				Suicide becomes the driving force behind a commitment to suicide prevention which enables personal meaning-making. Role to construct and present an acceptable public storyline and image of the lost person. Preserving reputation of the deceased. Lastly, suicide seen as a mishap which needs to be dealt with.		
6	J. M. Fielden (2003) Australia	Exploring the different life-worlds after a loved one has completed suicide.	In-depth unstructured interviews using narratives as guided conversations using Hermeneutic phenomenological analysis. (n = 6) Recruited through two voluntary and one public health agency.	“Throwness” - suicide survivors moved through four modes of being-in-the-world characterised by 13 life-worlds or themes. Surviving suicide was a transformative process that in time enabled survivors to discover new ways of understanding and relating to the world. Significance of the loved one to the survivor. Experiencing the grief Survival mode. Paralysed by fear and guilt /Experiencing support. Physical reactions to grief/ Managing the grief /Early days after the suicide/ Sleeping and dreaming/Taking	The intensity of grief and trauma. Social experience and stigma. Meaning-making, including making sense of events of the death. Post-traumatic growth and identity.	31

				space /Spiritual beliefs /Activities as a Survivor. Survival - experiencing blame and stigma. Silencing through the experiences of shame and stigma. Distress through perceived omissions of health professionals’ oppressive health professional practices. Milestones as signals for moving on. Realisation/experiencing the reality /discovering the body. Keeping memories alive – using their loved one’s physical space (room) and managing anniversaries way of helping to take the mind off the intensity of grief. Moving on - making meaning of events further on why, why, why – reflecting on their sense that all had not been well/ A sensitive nature.		
7	Honeycutt A., and Praetorius R (2016) USA	Exploring experience of survivors of suicide, asking:	Questionnaire designed to gather narrative descriptive information—some asked in open-	Findings suggest that (a) there are many different relationships in which people are bereaved, (b) survivors use many coping strategies, and (c) they use numerous terms to describe themselves.	The intensity of grief and trauma. Social experience and stigma. Meaning-making.	20

		(a) who self-identifies as bereaved by suicide, (b) their coping strategies, and (c) what they prefer to be called.	ended format and others in multiple-choice format; no scales or scaling questions. People receiving the American Association of Suicidology's Surviving Suicide (n = 293).	People wish to be called 'suicide survivors'.	Post-traumatic growth and identity.	
8	Q. A. Hunt; T. A. Young; K. M. Hertlein (2019) USA	Exploring the experience and process of long-term suicide bereavement.	Grounded Theory interviews using semi structured question. (n=10) 18 years & over. Self-identified as a suicide loss survivor/ more than 5 years since death. Participant ages through social media, peer	Three categories emerged: (1) one overarching harmful feeling of being a suicide loss survivor (responsibility), (2) one of how loss survivors learned to be okay (social and familial support). Within social and familial support the loss survivors discussed: (a) ways in which they did not receive social and familial support that increased of their feelings of responsibility, and (b) ways in which they did receive social support that helped them to learn to be okay. (3) one of how they have found a way to "be okay" with the death (meaning-making). When discussing their understanding (meaning-making) of their loss participants discussed (a) ways to	The intensity of grief and trauma. Social experience and stigma. Meaning-making.	32

			nomination, and snowball sampling.	maintain a connection with their lost loved one (continuing bonds) and (b) how they have reframed the suicide. Within responsibility, some experiences appeared (a) due to the feelings of responsibility and (b) some increased the feelings of responsibility.		
9.	Krysinska K and Andriessen K (2015) USA-based website English-speaking	Exploring online memorialisation for those bereaved by suicide.	Thematic analysis was used to identify, analyse, and report themes within the collected online material. Study analysed 250 memorials dedicated to those who died by suicide. Two memorialisation websites: Faces of Suicide and Gone too Soon.	Fourteen themes were identified, ranging from sadness and expressions of love and other grief reactions of the bereaved, to acknowledgment of suicide and search for reasons for the death. Some of the bereaved wrote about their motives for posting an online memorial. Future studies should determine the impact of involvement in online memorialisation on the grief process of suicide survivors.	The intensity of grief and trauma. Meaning-making, including making sense of events of the death	25
10	Maple, M Edwards, H	Experience of parents	Narrative in-depth exploration using	Parents need to maintain a relationship with their child. The ways in which	Meaning-making.	27

	Minichiello, V & Plummer, D (2013) Australia	bereaved through the suicide death of their adult son or daughter.	three-tiered analytic technique/first analysing the narrative within/comparing narratives between stories/contrasting the narratives with the social and environmental context. (n = 22) Parental experiences following the suicide death of a young adult child.	parents do this is many and varied ranging from public and private memorials to internal dialogues Key finding the importance of acknowledging and honouring the need for bereaved individuals to form new ways of connecting with their deceased child following their death. The practices associated with remaining connected emotionally and/or spiritually occurred in the absence of socially condoned ways in which to honour such memorial places and spaces. Public expression of grief involved organisational roles.	Post-traumatic growth and identity.	
11	Oulanova, O and Moodley, M (2014) Canada	The experience of being bereaved by suicide and volunteering with others bereaved in the same manner.	Interpretative phenomenological analysis (IPA). Semi-structured interviews. Questions asked directly about volunteering in	Three core themes weaved through their accounts: (a) transformative process; (b) engaging with silence: finding a voice and lending an ear; and (c) reaching out: countering loneliness and isolation linked with volunteering. Volunteering roles taken up.	Meaning-making. Post-traumatic growth and identity.	23

			relation to being suicide survivor (n = 15) individuals bereaved through suicide who had been volunteering with others bereaved in the same manner.			
12	Peters, K Cunningham, C Murphy G and Jackson D (2016) Australia	Experiences of what bereaved family members find helpful and unhelpful following a suicide bereavement.	Narrative. Self-selecting through snowball sampling and targeting advertising. (n = 10)	Some professionals were felt to understand. Experiencing compassion: “I remember that bit of kindness”. Or responses by agencies are often insensitive and not aligned with the needs of those bereaved. e.g. Facing insensitivity: “just so inappropriate”. Seeking support from others bereaved: e.g. “you knew that they understood”.	The intensity of grief and trauma. Social experience and stigma.	23
13	Peters, K Cunningham, C Murphy G and Jackson D (2016) Australia	Insights into stigma as experienced by suicide survivors.	Narrative. (n = 10) People bereaved by suicide.	Feeling blamed, shamed and judged. Feeling isolated/rejected by friends and community. Feeling silenced. Feeling the burden of others' discomfort.	The intensity of grief and trauma. Social experience and stigma.	27

				Stigmatisation of the bereaved by suicide had detrimental effects on their relationships and their help seeking behaviours. Further, due to stigma imposed on them by others, participants were denied the opportunity to tell their stories which further complicated their grieving process.		
14	Peters, K Murphy G and Jackson D (2013) Australia	Perspectives of family survivors of the events leading up to the death.	Narrative. (n = 10) Self-selected after a media release advertising.	Deep sense of loss and continued to express their grief, sadness, and regret over the events surrounding the suicides. Desire to contribute something positive e.g. some participants were actively engaged in volunteer/activism works in the area of suicide bereavement and mental health support Role in relation to keeping deceased from taking their lives: Nobody Talked to Me: Exclusion of Family Members from Treatment Information. Purposeful Indications of Intent to End Life. They Sill Ignored It: Disappointment with Health Services.	The intensity of grief and trauma. Social experience and stigma.	23
15	Powell K A & Matthys A (2013)	The effect of being bereaved	Interpretive approach.	Lack of uncertainty and peace with the loss: Felt security.	The intensity of grief and trauma.	23

	United States and two provinces in Canada	by the suicide of a sibling.	Open-ended, semi-structured, interview questions (n = 45) Participants who had lost a biological sibling to suicide.	Fluctuating uncertainty and continuing loss: A lack of knowledge. High uncertainty and perpetual loss: A need for closure and information. Avoiding information/seeking information. Connecting with other survivors of suicide. Seeking and disseminating information about suicide. Communicating positive memories.	Social experience and stigma. Meaning-making Post-traumatic growth and identity.	
16	Sheehan, L. et al (2018) USA	The experience of families bereaved by suicide.	Thematic analysis of focus group data and community-based participatory research process. (n = 62) With secondary analysis of qualitative data focusing on stigma directed at bereaved families.	Bereaved families were seen as emotionally strong, victims of the suicide, or as contaminated by their association. Themes describing experience of stereotypes, prejudice, and discrimination. Families encounter pressure to keep the suicide a secret and experience withdrawal of support systems. Results suggest needs for evidence-based programs to address both public and internalised stigma experienced by bereaved families. Bereaved families were viewed as contributing to their loved one’s death	The intensity of grief and trauma. Social experience and stigma.	22

				through abuse, neglect, denial, or failure to provide adequate help.		
17	Smith, A Stephen, J Das Nair, R (2011) UK	Exploring post-traumatic growth following bereavement by suicide.	Interpretative phenomenological framework used with transcribed interviews. (n = 6)	Two superordinate themes, with three ordinate themes in each, were identified: (a) positive growth ("life view," "knowledge of self," and "relation to others") and (b) social context ("gaze of others," "public guise," and "solace of other survivors"). Suicide survivors gain extra insights due to their experiences but are reluctant to acknowledge that they do.	The intensity of grief and trauma. Social experience and stigma. Meaning-making. Post-traumatic growth and identity.	26
18	Spillane A. et al (2019) USA	The experience of suicide-bereaved family members of coroner's courts.	Thematic analysis. (n = 18) Qualitative semi-structured interviews explored experience of the inquest process.	Most family members experienced distress and fear as a result of several elements of the inquest process. Some participants had positive experiences, but these did not outweigh the distress experienced by most family members regarding their overall experience of the inquest process. Four overall themes of family members' experiences of the inquest process: "inquest as fearfully unknown", "structural processes of the inquest", "enduring public and private pain to obtain answers" and "gaining answers and making sense".	The intensity of grief and trauma. Social experience and stigma. Meaning-making.	21

19	Van Dongen C. (1991a) USA	Experience of suicide-bereaved.	Use of GT terms. (n = 35) Participants were identified via death records and snowballing.	Agonising questioning was identified as a core concept. If death seen as preventable or not is significant. Also: Emotional Turmoil (including Guilt), Physical Disturbance, Cognitive Dissonance, Relationship with deceased seen as significant factor in experience of bereavement.	The intensity of grief and trauma. Meaning-making.	20
20	Van Dongen, C (1991b) USA	Experience of suicide-bereaved linked to findings specifically focusing on use of family practitioners and support for bereavement.	Use of GT terms. (n = 35) Participants were identified via death records and snowballing.	Physical Disturbance linked to findings specifically focusing on use of family practitioners and support for bereavement. Survivors suggest improvements to supportive care with examples. Additional information using percentages of those described with specific experiences and emotions linked to requirements for specialist care in bereavement.	The intensity of grief and trauma. Meaning-making.	20
21	Van Dongen C (1993) USA	Experience of suicide-bereaved regarding the nature of their	Use of GT terms. (n = 35) Participants were identified via death	69% of Ps reported experiencing strong social support, while 26% reported at least 1 experience of perceived stigmatization related to the suicide.	The intensity of grief and trauma. Social experience and stigma.	20

		social relationships, including the perceived social support from others.	records and snowballing.			

6.9. Critical Analysis – Categories

Table 11. Categories identified across the literature

The following categories were identified across the literature. These lead to discussion of the conceptual themes of anticipation and ambiguity (6.10) and how this relates to the post bereavement challenge of meaning making in the face of loss after a suicide.

Categories	**Discussion See section**
Meaning-making including making sense across time.	6.9.1
The intensity of grief and trauma.	6.9.2
Social experience and stigma.	6.9.3
Post-traumatic growth and identity.	6.9.4

6.9.1. Meaning-making

All the research in the review, referred in some way to the challenge of the bereaved to make meaning of their experience of loss due to suicide. Making meaning following a death is recognised as a crucial stage of grief involving both cognitive and emotional 'tasks of grief' (Worden, 2018, p.11).

6.9.1.1. Making sense of the events of the death

Research identifies that the need to explore the events leading up to and around the time of the death is necessary for the bereaved to make meaning of the death and that meaning-making requires the bereaved to construct a chronology of the events leading up to and at the time of the death (Van Dongen, 1991). Two of the articles look at the experience of the bereaved of the coroners' court, identifying that a key issue for those bereaved is to find out about what happened (Biddle, 2003 and Spillane, et al. 2019). Both identify that having access to information about the circumstances of the death, is key to the capacity to grieve, both in relation to the expression of grief and meaning-making. Van Dongen, (1991) uses the term 'cognitive dissonance' (p. 226), first used by Festinger (1966), and how this appears to be the most intense amongst the bereaved who had no prior expectation that a suicide might occur and that this leads the bereaved to experience a strong pull to obtain information to explain how the suicide had happened. Van Dongen, (1991) describes this dissonance as a difficulty in processing the changes in relation to their understanding of the person who has died.

Time is mentioned by Fielden, (2003) as significant in how the bereaved understand events and how this suggests progress and positive change. He identifies four 'modes of being in the world' (p. 80): Thrown-ness, Survival, Searching, Moving. These concepts describe the need for the bereaved to construct a chronological and meaningful narrative of what happens to them after the death. Another review (Chapple and Hawton, 2015) stresses the need of the bereaved to comment on the impact on them of their experience of suddenness or shock after the death. The action and process of bereavement across time is a significant factor in all three of these studies pointing to how this contributes to the emotional experiences of those bereaved by suicide.

6.9.1.2. Searching for answers and relationship to the deceased

This need to find answers about the events of the death are closely related to how the bereaved make sense of the person who has died and their relationship to them. Castelli (2013) identifies a significant role for the bereaved as they feel drawn to construct and present an "acceptable" public storyline and image of the lost person, to preserve the reputation of the deceased. This is described as "reconstructing the figure of the suicide completer" and this reconstruction enables the bereaved to find meaning as they make sense of who has died and their relationship to them (p. 325).

Examples from the review draw attention to the need for those bereaved by suicide to connect and maintain their relationship with the deceased, despite the disruption to the relationship by the suicide. Fielden, (2003) describes searching for the deceased and the ongoing endeavour to keep memories about the lost person alive, for example spending time or sleeping in their space to experience being close to them. Hunt et al. (2019) give the example of a participant keeping the belongings of the deceased: "I have an old Sony Walkman that he gave me that doesn't work anymore. I've tried, but just can't bring myself to get rid of it." (p. 341). This needing to find ways of maintaining a connection with the deceased can range from public and private memorials to internal dialogues. The public expression of grief (Maple et al., 2013) enables ways of maintaining spiritual and emotional ‘connections’ to the deceased via ‘memorial spaces and places’ (p. 56).

6.9.2. The intensity of grief

Emotional aspects of the experience of being bereaved by suicide were discussed in all included articles, and most describe intense negative or painful experiences, often with participants naming shame and guilt as particularly significant aspects of their experience. Azorina et al. (2019) includes a participant describing this, “At first I did not tell any of my close friends or family because it was still too painful to talk about” (p. 5).

Various coping strategies (Fielden, 2003; Honeycutt and Praetorius, 2016) were described by the bereaved to counter the emotional or other negative experiences of bereavement. Oulanova et al. (2014) describe participants as finding it helpful to make ‘expressions of grief and sadness’ (page 156). These expressions are made privately as an individual but many expressions are made with other people, often family and friends (Sheehan et al., 2018).

The bereaved experienced that some people did not understand their situation or feelings, seeking instead the company of those also bereaved by suicide (Powell and Matthys, 2013). Some of the bereaved feel that their experience is too painful for others to bear, hide their feelings and feel they need to isolate themselves (Azorina, et al, 2019).

To have social contact is described as part of a coping strategy, with the lack of social support described as potentially very damaging to the expression of grief and bereavement (Barlow and Coleman, 2003; Castelli, 2013; Fielden, 2003). Oulanova et al. (2014) found that the bereaved benefit from ‘engaging with silence, finding a voice and lending an ear’ (p. 156).

The experience of grief is also expressed in other ways than emotional, as both a physical experience and intellectual task (Van Dongen, 1991). The ‘cognitive dissonance’ described by Van Dongen (1991) is also described by other later studies as part of the need to find out about the events of the death and make sense of these in a wider endeavour to understand how this death has taken place. (Biddle, 2003; Castelli, 2013; Peters et al., 2016; Spillane et al., 2017). Suicide is frequently experienced by the bereaved as sudden and unexpected

(Krysinska and Andriessen, 2015) and may have included the trauma of finding the body (Barlow and Coleman, 2003).

6.9.3. Social Experience and stigma

Experience of stigma is found in all the papers and might be called a defining feature of the experience of those bereaved by suicide. Spillane, et al. (2019) and Biddle (2003) identify the experience of the insensitivity of organisations such as coroners and other professionals. Peters et al. (2016 (b)) find that agencies are often 'insensitive and not aligned with the needs of the bereaved' and Biddle (2003) suggests that this difficulty in using the court to arrive at 'meaningful and acceptable account of the death', interferes with the 'necessary grief work' (p.1042).

This may lead to an experience of rejection by the community adding to the sense of isolation. Peters et al. (2016) identify how stigmatisation relating to suicide by the community is experienced by the bereaved and becomes detrimental to their relationships and help-seeking behaviours. The resulting lessening of their capacity to 'tell their story' p.253) is a complication to the grieving process.

This need to connect with other survivors of suicide (Powell and Matthys, 2013) is a way of finding a social context that allows expression, particularly the need for information and closure. The significance of the social context enabling the expression of grief is identified as core to the process of change of identity and meaning-making that contributes to the ongoing process of bereavement.

The social context of the experience of bereavement by suicide is identified in all the articles as having great significance. This is sometimes linked as being a key to more successful and less painful experience of grief and bereavement, for example 'healing alliances' are created by family members as they engage in the painful process of grieving, moving towards family 'transformation' (Barlow & Coleman, 2003). The quality of relationships to others is affected by the death (Azorina, et al. 2019), with attachments to others becoming both overprotective or avoided.

The experience of stigma was looked at closely in seven of the studies (Azorina, et al. 2019; Biddle, 2003; Castelli, 2013; Fielden, 2003; Peters, et al., 2016; Sheehan et al., 2018; Van

Dongen, 1993). All find that stigma has a significant and negative effect on the experience of those bereaved by suicide. A further study also used the term 'taboo' to describe adverse effects for the bereaved, having consequences for the social acceptance of the death and public displays of mourning (Azorina, et al. 2019). A further two studies identify feelings of blame and coping with the judgemental 'gaze of others' (Smith et al., 2011) and (Barlow & Coleman, 2003), as well as 'feelings of responsibility' (for the death) (Hunt et al., 2019).

Stigma was described as occurring within a social context but also having the consequence of becoming internalised by some of the bereaved (Sheehan et al. 2018), adversely affecting their capacity to use social support to keep the cause of death a secret, and to preserve the social reputation of the deceased (Castelli, 2013).

6.9.4. Post-traumatic growth and identity

Fielden (2003) identifies a transformative process that enables new ways of understanding and relating to the world and describes this experience as post-traumatic growth; however, it also notes that participants are reluctant to acknowledge this growth. Castelli (2013) describes how the experience of suicide becomes the driving force behind a commitment to prevent suicide and links this to personal meaning-making. Meaning-making can appear both in relation to the social context of the bereaved as well as relating to an individual sense of meaning, for example personal existential meaning-making (Castelli, 2013). The bereaved also find that they and others close to them need to be "engag(ed) in the painful process of personal re-definition and family transformation", (Barlow & Coleman, 2003, p. 188).

Oulanova, Moodley & Seguin (2014) present how volunteering roles taken on by the bereaved enable a transformative process countering loneliness and isolation. There is consistency in the use of the term 'survivor of suicide', used in sixteen of the articles. Honeycutt and Praetorius (2016), with a wider pool of participants, found that numerous terms were used to describe the self after the suicide bereavement, with the preference to be called a 'suicide survivor'. Two of the articles identify participants as having made some progress towards more positive experiences which are identified with a variety of terms. Barlow & Coleman, (2003) identify 'positive growth' in relation to life view, knowledge of self and in 'relation to others' (p.199). Becoming active socially is described as a potentially rewarding way to make meaning and improve the experience of bereavement, variously, taking up volunteering (Peters et al., 2013); disseminating information about suicide (Powell and Matthys, 2013); commitment to suicide prevention (Castelli, 2013); and seeking the solace of others by creating healing alliances (Barlow and Coleman, 2003).

6.10. Discussion

This review identifies common concepts and repeated patterns showing a commonality of experience for suicide survivors and answering the literature review question. The models and theories that are drawn upon by the studies in the review strengthen their findings and have been used by some of the researchers to deepen their understanding of the initial interviews and include ambiguous loss (Hunt, 2019), attachment (Azorina, 2019), stigma (Peters et. al. 2016), post-traumatic growth (Barlow, 2003 and Smith, Stephen, & Das Nair, 2011) and continuing bonds (Hunt, 2019).

Suicide survivors within this review are described as having difficulties in finding understanding and acceptance of their bereavement and needing to find others that will understand their experience of grief. Although a more complex grief reaction can occur due to deaths that are not caused by suicide, difficulties in meaning-making are associated with deaths that might be caused by events that could be described as sudden, unexpected, or untimely (Boelen and van den Bout, 2010). More complicated grief reactions that occur following deaths that might appear to be more expected, such as the death of a person in old age might be expected only for those bereaved with individual personal susceptibility or vulnerability following a loss, for example, those with an insecure attachment style (Parkes, 2006). These models and theories of grief are influential in bereavement care and the understanding of grief and bereavement, and will be considered in relation to both this review of suicide bereavement, and the research question of this thesis. (See Chapter 7 Discussion).

This critical interpretive synthesis that found that the common experience of being shocked by this sudden death is linked to the need to find out about the events leading up to the death, with this particularly appearing in studies relating to the experience of inquests (Biddle, 2003 and Spillane, et al. 2019), highlighting these social arenas as having potential value to the bereaved but having a negative outcome if the needs of the bereaved to explore the events are not enabled. The lack of opportunity to be with the person when they died leads to cognitive dissonance, described by Festinger (1966), as the difficulty of processing the events and their implications, and leaves unfinished questions relating to how they died and why they died (Van Dongen, 1991a).

As noted in the findings it was important for the bereaved to be enabled to make sense of the chronology of the death. A particular characteristic of suicide bereavement is that there is less likelihood of prior anticipation and that afterwards there is a lack of information, with both described as being a hindrance to the capacity to grieve that can intensify or prolong bereavement. In some situations of suicide bereavement, the bereaved may have some preparation of their intentions and reasons, however Wojtkowiak et al. (2012) recommend more attention be given to the relation between grief responses and expecting the suicide of a loved one.

Boss (2010) describes how suicide can be described as an ambiguous loss if, for example, there is no note, leaving the bereaved with ambiguity in relation to key aspects of their experience with additional work to process as they struggle to make sense of the death. The way in which the deceased has chosen to die contributes to the sense of unpreparedness and of not knowing what the deceased might have been feeling at the time of death (Chapple and Hawton, 2015). This ambiguity towards the deceased and how they chose to die is discussed by Castelli (2013), Fielden (2003) and Hunt et al. (2019) who note the significance of the ongoing, post-death relationship with the deceased and how this re-working of the relationship with the deceased is complicated by the nature of the death.

Being able to make sense of the events and actions leading to the death impacts on the capacity of the bereaved person to make sense of the relationship they had with the lost person. The painful and intense searching for the person described in many of the accounts within this review can be understood as a grief process enabling the creation and maintenance of a continuing bond (Klass et al., 1996) to the lost person after their death. As well as struggling to make sense of the relationship to this key person, the bereaved are described as experiencing biographical disruption. The grief process then requires significant work to remake and reconstruct a personal narrative, for example in finding ways of naming themselves, sometimes as ‘suicide survivors.’ This intrapersonal work is affected by their capacity to use the social groups that might support or offer spaces to find models of coping and ultimately enable post-traumatic growth (Fielden, 2003).

The experience of the pain of grief is recorded throughout the review studies, often described as feelings of shame, guilt and self-blame (Barlow & Coleman 2003). These feelings are more likely to be hidden and this contributes further to the isolation of these bereaved people, sometimes affecting their capacity to use interpersonal avenues of support such as their family, friends, or social support groups (Smith et al., 2011). Their capacity to use relationships with others will also depend on how the people in the social groups that they seek out or find view and react to suicide (Oulanova et al., 2014).

The reported social interaction with other people and groups indicates a common experience of stigma for suicide survivors. Further, the social context and perceived stigmatisation appear to affect bereaved people, reducing their capacity to seek support from others and affecting their capacity to make meaning of the death and of their relationship with the deceased. However, for some suicide survivors, post-traumatic growth is possible (Fielden, 2003) and is associated with seeking out others in similar situations, finding purpose in volunteering and campaigning and making meaning of the death in relation to the events of the death (Castelli, 2013) and a continuing relationship to the person that died (Azorina, 2019).

6.10.1. Limitations

Some of the studies had less clarity about their methodology without having a consistent description of approach, for example using terms such as 'using a qualitative interpretive approach' without clearer explanation of methodology (Powell and Matthys, 2013) and 'qualitative semi-structured interviews exploring the experience' (Spillane, et al., 2019). In both cases the Hawker rating was the lowest included at 20 (Hawker et al., 2002). However, both added insight into aspects of suicide bereavement less well covered in other studies, for example Spillane et al., (2019) being more recent to a second review about the impact of the inquest or court (Biddle, 2003).

6.10.2. Strengths

Despite the limitations discussed, the studies that were included were appropriate in answering the review question and enabled a critical synthesis of the phenomenon identified for this review. The review has offered theoretical openness (Green and Thorogood, 2018, p.277), using critical interpretive synthesis as an appropriate match to the constructivist paradigm and constructed grounded theory methodology used in this research.

All the studies use a qualitative methodology that endeavours to enable the participants to express their experience and uses researcher reflexivity to try to limit any prior expectation or bias from the researcher. There were varying degrees of description of the methodology of the studies, but they were all within a range that might be regarded as having something useful to offer to the review. The findings appear to identify some consistent concepts, strengthening their usefulness to the understanding of the experience of being bereaved by suicide and contributing to the Discussion in Chapter 7. By utilising an identifiable and tested approach to the synthesis (Dixon-woods et al., 2006) the reliability of the synthesis results is further strengthened.

The review was conducted rigorously with methodological openness (Green and Thorogood, 2018, p.277), the searches are replicable and the process of the literature search ensured a consistent and comprehensive identification of relevant articles. Inclusion of poorer quality literature was guarded against by close attention to recording and the use of quality tools such as Hawker et al. (2002).

I was aware of the importance of the wider social context surrounding suicide and stigma and by choosing a critical interpretative synthesis; the review reduced the possibility of imposed or prior expectations that might have limited findings and that actively include researcher reflexivity. The concepts identified in the review occur consistently over a period of more than 30 years, across different populations, and in different western countries, suggesting the rigour of the findings and their applicability to a variety of western cultural settings. Although no claim to generalisability is made, the review findings have a transferable role to inform understanding of the experience of those bereaved by suicide and will contribute to the conceptual understanding of research participants that are bereaved by AS. (See Chapter 7).

6.11. Summary

The methodological approach of the literature review, using a critical interpretive synthesis presented a coherent overview of the key concepts and answered the review question. The review found a consistent set of experiences for those bereaved by suicide. These include similar patterns of grief, social experiences including inquests, feelings of stigmatisation and social isolation, and the need for meaning-making, requiring the bereaved to review both their relationship to the deceased and their own identity. Articles recommended closer attention to, and more focused support for, these bereaved, particularly in view of the social context. The critical interpretive synthesis is further considered in the next chapter, informing full discussion of the findings, a presentation of the constructed grounded theory as a response to the initial research question and moving to final conclusions.

Chapter 7. Discussion of the theoretical model of Enabling and Campaigning

7.1. Introduction

This study is the first to explore the experiences of those living in the UK bereaved by AS and has identified the theoretical concepts of Enabling and Campaigning. This theory offers insight into the dynamic relationship between the role of enabling AS before death, and afterwards, how campaigning in support of AS can be viewed as part of this experience, and as a way to make meaning of the experience of AS bereavement.

The grounded theory of the experience of enabling AS described in Chapter 5, is reviewed in light of theories of anticipatory grief with consideration of the emotional and cognitive tasks that might be experienced by those bereaved by AS and how opportunities for anticipatory grief may be constrained by the requirements of the role of enabling. The influence of both the feared anticipated death and the need to honour the wishes of the deceased are recognised as being the powerful drivers contributing to the stress of taking on the role of enabling the AS.

The critical interpretive literature review of suicide bereavement discussed in Chapter 6 is examined alongside the theory of enabling and campaigning, and discussed showing a relationship between stigma and the experience of becoming a suicide survivor (Peters et al., 2016 (b)). This chapter will review the role of stigma and suicide bereavement and how this influences and affects these participants in their choice to become campaigners. The chapter discusses how this both challenges and allows relief from the stigma experienced from their role as enablers of the AS. This creates opportunities for the bereaved to become open and socialise with others who have had a similar suicide bereavement. The grounded theory of campaigning following assisted suicide also described in Chapter 5, is discussed in relation to the findings of the critical interpretive review that identified the possibilities for post traumatic growth with research and theories of post-traumatic growth (Calhoun and Tedeschi, 2014) and bereaved family activism, (Cook, 2020).

The theories of enabling and campaigning are further explored with a model of grief, the dual process model (Stroebe and Schut, 2010) which is recognised as making a valuable contribution to the current understanding of grief and bereavement (Stillion, 2015). The dual process model (Schut, 1999) is applied to the experience before the death occurs, corresponding with the role of enabling, and after the death, the dual process model is used to identify processes involved in campaigning, a compensatory dimension of grief. The dual process model is used to identify this relationship as a dynamic and regulatory process of oscillation of adaptive coping, where both confrontation and avoidance of loss and restoration stressors are experienced, and coping and meaning-making take place.

This is the first use of the dual process model to understand experience before a death, exploring the anticipatory grieving involved in enabling AS, and showing that the model can be applied to describe pre-bereavement experience. This is further extended to consider how it might bring clarity to understanding the experience of the roles taken by carers of those following the diagnosis of a life-limiting illness, also specifically in relation to the role of enabler of the AS.

Elements of the experience of enabling AS and campaigning after this loss are identified, and show how they can usefully be described using the loss and restoration-oriented activities identified by the dual process model. This is applied to both understanding and planning for the needs of those caring and grieving for someone who dies following a assisted suicide. There is further exploration of how the grounded theory of enabling and campaigning might be applied using the dual process model to develop care of those bereaved by a assisted suicide. Implications for future research and clinical practice are discussed both within the UK and in areas that have a legal framework for assisted suicide.

7.2. Anticipatory grief during the pre-bereavement phase for those bereaved by AS

The cognitive and emotional tasks of grieving have been observed as playing an important role in the experience of grief (Worden, 2018). Anticipatory grief was identified as being significant as part of the experience of being a carer for those with a life-limiting illness (Sweeting and Gilhooly, 1990) and it has been suggested that opportunities to begin some of these tasks before the death can be beneficial (Rogalla, 2020).

Schulz et al. (2015) found families that were able to be supported through advanced care planning in a care home setting, were better ‘prepared’ for the death and that this facilitated anticipatory grief that improved post-bereavement adjustment, particularly to their sense of identity after the death. However, Nielsen et al. (2016) questioned the assumptions that grief work takes place before the loss or that it alleviates bereavement distress, finding that ‘high preparedness’ was associated with improved caregiver outcome but that this might not always take place, identifying that for some carers there was ‘low preparedness’ despite the prior knowledge of the death.

Unlike those bereaved by suicide, the participants in this thesis that were enabling the death were able to know in advance of the impending death and, for many, knowing the exact time and date that the death would occur. Many of the participants in this thesis described how the need to complete the tasks required to enable the death took precedence over the opportunity to make any emotional expression or anticipatory grief. With only one participant describing how she had valued the opportunity to spend time with her father in the weeks before the AS, and to express emotions as they took opportunities to tell him what he meant to her and her children.

There is a complex inter-relationship between individual and social factors affecting family members caring for someone during an assisted or hastened death. Lowers et al. (2021) identified key themes for carers of those choosing voluntarily stopping of eating and drinking (VSED) to achieve a hastened death. Caregivers felt great responsibility to ensure this choice but felt unsure about how to operate during this time, feeling that they had no ‘social script’ to guide them during this life-changing event (Lowers, 2021 p.378-80). As advocates of this decision, they worried that health care professionals might challenge this choice, feeling that there were ‘risks’ to the ‘legitimacy’ of this choice.

The development of a theory grounded by the findings in this thesis, suggests that for participants living in a country without a legal framework for AS, there is heightened anxiety that contributes to a challenging time for those bereaved before the death takes place (5.4) and that this might impede opportunities for anticipatory grief. They are anxious that the chosen death may be prevented from taking place, thus not honouring the wishes of the deceased and that the feared and anticipated death will then take place. This feared and anticipated death is the powerful driver that overcomes all the other difficult challenges involved in the choice for the assisted death. This can include earlier experiences of other deaths and is linked to beliefs about diagnosis that an unbearable death would take place without the alternative provided by the AS. As the planned AS is seen as an escape from the feared and anticipated death and is welcomed and sought after by the relative, the need for a practical response to enable the situation becomes an imperative.

Being the enabler of the AS involved great responsibility for arranging the death and caused great emotional conflict, as these bereaved felt compelled to enable their relatives' wish to die and to honour their wishes, yet also struggled with anxiety that needed to be managed to meet the demands of their role.

7.3. The role of enabling and reduced opportunities for anticipatory grief

All participants spent time describing the period leading up to the death as being taken up with the role of enabling the AS, and described little of their feelings about the loss, rather describing a time of being 'business-like' and busy with the arrangements for the AS. For those enabling the AS, the unusual and socially sensitive nature of deaths due to AS and suicide led them to gatekeep information about the death, and that this need to keep the plans secret impeded some opportunities for a wider support network than those directly involved in the AS.

The secrecy involved in enabling an AS is found to have lessened the opportunities for those involved in the arrangements to talk to anyone else to consider the current or future emotional impact of the loss. This might be understood as reducing opportunities for restoration-oriented activity, to express and process grief (Stroebe and Schut, 2010).

The grounded theory of enabling makes links between how enablers of the assisted suicide are required to suspend their feelings and be business-like, with the negative experience of being less able to express themselves openly, to get support and the resulting experience of isolation may limit opportunities for social support. Coelho (2020) found that someone caring for a family member with a life-limiting illness needed to regulate their emotion in relation to separation distress brought about by the anticipation of the future loss as well as current losses within the relationship as the illness progressed. This emotional regulation was noted as being a significant aspect of the tasks required of family members, relating to separation distress, but also in relation to traumatic distress which included uncertainty of illness, images of degradation as the illness progressed and of feelings of impotence in the face of the illness. For participants enabling AS, the possibility of being confronted with aspects of the traumatic quality of the illness and future, anticipated and feared images of degradation were avoided by arranging the AS. Additionally, any impotence that a family member might feel in the face of the impending death is largely avoided by the action of enabling the death.

Deaths that are socially disenfranchised (Doka, 2002) encourage the bereaved to hide their experience, and this secrecy and isolation has been linked to increased vulnerability to complicated grief (Raphael, 1988). The social value and comprehension of an experience of loss are linked to the individual's right to the expression of grief within social groups, and the lost person or the experience of the loss may be socially recorded as having less value, for example, the death of someone due to a suicide or other less socially acceptable deaths such as drug or alcohol addiction (Fowlkes et al., 1991).

This vulnerability to complicated grief is associated with needing additional intervention and support (Raphael, 1996) and for suicide with an increased post-bereavement risk that includes increased risk of suicide (Andriessen, 2014). For those enabling an AS and feeling pressure to meet the wishes of the dying person to avoid the feared death there may also be an intrinsic double bind in both wanting to help someone to die, but also wishing they would not, in that the active role played by those enabling the death ultimately removes the loved person. This unusual emotional dilemma with additional cognitive dissonance (Festinger, 1966) may contribute to the frequently noted experience of the event of the death feeling unreal or surreal, and research has noted that experiences of dissociation or unreality can present as a reaction to traumatic deaths (Holland and Neimeyer, 2011).

Participants who knew about the death in advance, were all able to give their own rationale for the AS, with all of these participants being clear that they believed this had been the only decision they could have made, with two exceptions where the participants were less sure and expressed considerable regret. During the period before the death the relative taking on the role of enabling the death will need to begin the complex internal rationalisation for their actions, and participants related feeling they had not been able to choose this role and, whilst agreeing with it, nonetheless had felt compelled to support their family member in this way.

A literature review of families’ experiences of assisted dying taking place in countries with a legal framework (Gamondi et al., 2019a) also found that there was significant cognitive work involved in reaching a shared ethical stance about the decision. (Gamondi, 2013) in interviews with bereaved families in southern Switzerland, identified three ethical dilemmas: “the appropriateness of the patients’ choice of assisted dying, the depth of their involvement in it and their possible selfishness in wanting the patient not to die” (Gamondi, 2013 p. 1639-44.) Although this research takes place in a country with a legal framework, some families express significant concern about their legal position (Gamondi, et al. 2013) with specific concerns “regarding the necessity of dealing with the routine procedures conducted by authorities after death” (p 1101).

7.4. Stigma and suicide bereavement

The systematic literature review forming part of this thesis (Chapter 6.) used critical interpretive synthesis and supported the thesis findings by identifying that stigma is a common negative experience of being bereaved by suicide. To explore and understand the findings of the experience of those bereaved by AS, consideration is given to the critical interpretive synthesis review of suicide bereavement, and a discussion of the themes that emerged from the review that might inform further understanding of assisted suicide bereavement.

Stigma is a complex and dynamic social process by which human differences are labelled and stereotyped in pejorative ways (Link and Phelan, 2006). Goffman (1969 p.19 – 31) notes that a person holding a stigmatised place in society will avoid prejudice by carefully managing information, and typically will not share this with others unless they are perceived as belonging to the same group. This process, whilst difficult to measure objectively, is experienced to varying degrees of severity having both personal and social consequences. For example, it might influence the feelings people hold about themselves (or believe others might hold about them), thereby affecting how they take up opportunities for social contact with others (Link & Phelan, 2006).

Stigma can cause adverse levels of physical and mental health (Hatzenbuehler, 2010) with stigmatised or morally illegitimate losses such as suicide, leading to those bereaved needing to gatekeep information to those who they feel have had a similar experience of loss (Weiss et al., 2006). Research identifying the risk issues relating to lower levels of social support available to the bereaved has been linked to increased grief, depressive symptoms, and to positive outcomes for those who perceive they have social support (Houwen et al., 2010).

The individual experience of grief and its behavioural manifestations are socially regulated, working to permit or deny an individual mourner's access to a socially legitimised grief, where society makes allowances for the incapacity and dysfunction during bereavement and enables social spaces to recognise the grief (Fowlkes, 1990). Not all losses are equally socially valued and accordingly not all losses fully set into motion the interpersonal practices of social consolation and accompanying rituals of grief, and will confine or prevent the establishment of facilitative social support (Doka, 2002). The social influence on the personal experience of grief has been noted in work by Doka on disenfranchised grief (Doka, 2002) (See 2.1.). This social pressure, arising from the stigma of suicide, increases the likelihood of hiding the experience and therefore having less opportunity to express feeings and gain social support from the usual networks available in many peoples' lives (Doka, 2002). These social networks are usually a positive experience and may help to normalise the experience of grief which also supports resilience (Cvinar, 2005).

7.4.1. Stigma and social isolation

Before the death, for those bereaved by AS, there is a dynamic interplay between stigma and the experience of isolation associated with the role of gatekeeping (Section 5.4.3). The relationship between secrecy and stigma leads to the necessity to become involved in the role of gatekeeping and causes the bereaved to experience further distress as part of their involvement in enabling the assisted suicide. The bereaved do not have the opportunity to share this challenging experience with others, inhibited by their beliefs of how others view assisted suicide and the current lack of clarity about the legal position in the UK. This appears to be likely to lead them to experience isolation, described by them as a negative outcome and attributed by them to the current legal position in the UK. However, this experience of isolation was also found for those bereaved by suicide in a study of families in Switzerland, that has a permissive legal framework (Gamondi, 2013).

The literature review in Chapter 6 found that those who are not able to find ways to challenge suicide stigma, might self-stigmatise with evidence that this can lead to poor self esteem, guilt and shame and a higher risk of complicated grief outcomes (Chapple, 2015). The possibility of negative self-stigmatisation was accompanied by an increased risk of becoming isolated due to the expectation of being judged by others (Smith & Das Nair, 2011).

After the death, the participants in this research involved in enabling assisted suicide sought out others who have been bereaved in this way, a similarity with those suicide survivors within the research in the literature review. The term suicide survivor has been recognised in studies as a term describing the experience of being bereaved by a suicide (Peters et al., 2016 (b)). The findings from the review showed that the use of self-help groups supports post-traumatic growth (Fielden, 2003) and meaning-making (Castelli, 2013) and the survivors need to review their identity within society in relation to the loss (Oulanova et al., 2014). This links to the grounded theory of enabling and campaigning found for the participants in this study, presented in Chapter 5.

An area of difference between suicide survivors and those bereaved by AS is the degree of warning that they feel they have had before the death. The literature review in this thesis (Chapter 6) finds that for those bereaved by suicide, unlike those bereaved by AS, there is less likelihood of having been prepared emotionally or cognitively for the death, for example by having warning of the impending loss. The bereaved are therefore shocked, having no opportunity to prepare themselves or to express feelings towards that person while they are still alive. Although some participants bereaved by suicide had, after the death, been able to look back to earlier events or previous suicide attempts and, in retrospect, see the signs, most bereaved by suicide described the event of the death as having been sudden and unexpected, and a shock and not giving any opportunity for anticipatory grief (Krysinska and Andriessen, 2015). Those bereaved by suicide are described as having increased risks for a range of "adverse outcomes" including "grief, social functioning, mental health and suicidal behaviour" (Andriessen et al., 2019). It is possible that those bereaved by AS but not informed of the plans or involved in the arrangements might have a similar experience of being less prepared.

7.5. Campaigning for assisted suicide and challenging stigma

The grounded theory developed from this study suggests that these participants sought to become involved in joining a campaign, both to manage and limit their anxiety and isolation, and, further, that this new role as a campaigner alleviates the earlier distress involved in enabling AS. The theory in this study has identified dynamic relationships between important experiential dimensions that take place before the death and are linked with experiences after the death.

Table 12. Experiences of enabling

Anxiety	**Lessening of Anxiety**
Isolation	Joining
Suspension of Feelings/Gatekeeping	Opening Up
Suffering from the AS Stigma	Challenging AS Stigma

Figure 3. below shows the dynamic relationship between experiences before the death as part of the role of enabling and how these pressures could be countered-balanced by taking on tasks related to campaigning. These theoretical concepts are paired in a dynamic relationship that offers the capacity to identify a negative or positive experience of the bereaved, and how out-of-balance or balanced any of these might become, both before the death and afterwards, part of the bereavement. See section 7.7. for a discussion of the dual process model and AS bereavement.

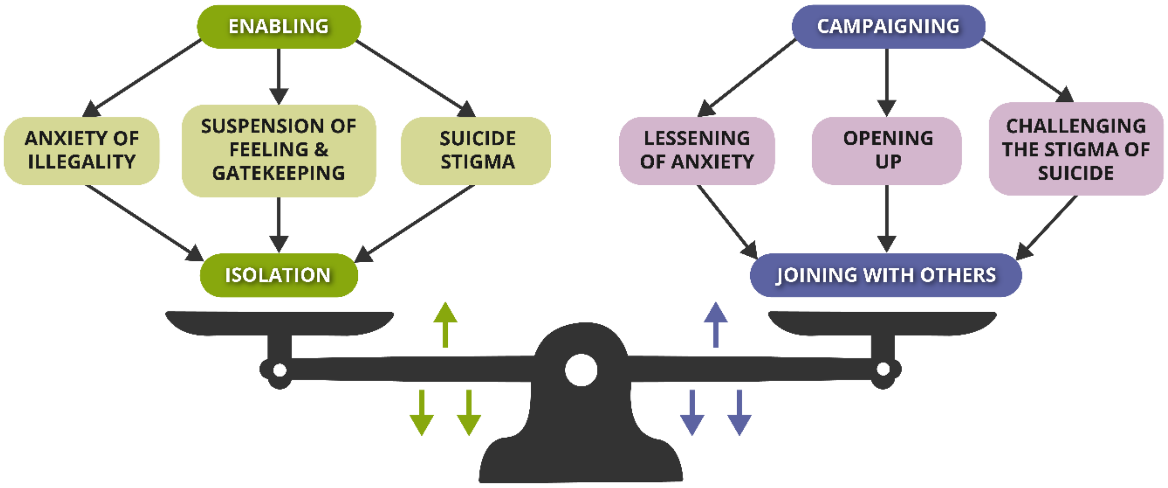


Fig. 4. The positive dynamic relationship between Enabling and Campaigning

Upon the successful completion of the AS, and the fulfilment of honouring the wishes of the deceased to die in this way, this theory identifies how the bereaved find ways to manage the experience of having enabled the death as part of their experience of being bereaved. Following the death due to AS, all but one of those involved in enabling the death became involved in campaigning, to bring about a change to the legal framework for assisted suicide in the UK, and the need to change the law was identified by them as the key issue causing them distress. Ten participants were members of Dignity in Dying (2021) and the findings identified a motivation to participate in the research to change the law in the UK where there is no clear legal framework to permit assisted suicide. Lowers (2021) found a similar motivation to bring about legal change from her participants, carers of those choosing to end their lives by voluntary stopping of eating and drinking.

The theory in this study identifies a positive dynamic relationship between enabling AS and subsequently becoming a campaigner encouraging potential support from others by engaging with campaigning groups working towards the legalisation of AS. The benefit of becoming able to speak to others who are perceived as sharing similar experiences and views following a bereavement, particularly where stigma plays a part, was noted in the literature reviewed in this study and was identified as forming part of the post-traumatic growth for some of those bereaved by suicide bereavement (Calhoun & Tedeshi, 2014). For those bereaved by suicide, campaigning often involved the prevention of suicide and bereaved family activism is discussed in the next section 7.6.

Joining and becoming part of these groups opens opportunities for dialogue with others who have had similar experiences. There is a positive relationship between campaigning, offering opportunities to share what has previously been kept secret, and this appears to alleviate some of the earlier distress of enabling, and following the death, challenges any experience of stigma they might experience due to their involvement in the AS (5.4). The experience of campaigning gives an opportunity for the creation of meaning-making to help account for the earlier experience of enabling, and the resulting social isolation and stigma.

7.6. Bereaved family activism and assisted suicide

The attribution of characteristics to people bereaved in unusual or traumatic ways, and associated with a disenfranchised grief, (Doka, 2002) makes research relating to the stigmatisation of those bereaved by murder or other traumatic deaths potentially relevant and useful to this study. Research exploring the effect of campaigning following traumatic deaths such as murder, car crashes or deaths due to negligence has highlighted how the voices of these victims create communities that can both recognise injustice and offer solidarity (Cook, 2020).

Bereaved family activism (Cook, 2020) describes how bereaved families confront perceived injustice and contribute to awareness raising and suggestions to improve public services or change the law. Within public debate and policy making there is growing importance given to the voices of those considered victims of injustice, for example those bereaved by violence having an impact on how the criminal justice system understands the needs of victims and gives space for these within the court or with new legislation.

As well as leading to social change, Cook (2020) also notes this can have positive personal outcomes for those bereaved by murder and that the ‘the practice of sharing these stories out of isolation can also encourage victims to make sense of lethal violence, reclaim control, and gain recognition from a wider community’ (Cook, 2020, p.115). Assisted suicide bereaved family members, might also be described as using this campaigning role as a restorative activity, helping them to make sense of enabling a family member or friend, to end their life.

This resonates with the critical interpretive literature review that identified that post-traumatic growth is associated with joining campaigning groups, although following suicide bereavement, this is to join groups set up to prevent suicide.

In a less positive way for the bereaved however, their grief can become commodified for public consumption (O'Leary, 2018) and where private tragedy can stigmatise individuals, specific groups or a community. Having indirect relationships to a person involved in an action or event that attracts stigmatisation, such as suicide, can indirectly affect the bereaved by association with an act or event (Wijk, 2017) and there might be little control for the individual in how these characteristics are attributed. As part of this stigmatisation, social processes can lead to the attribution of various characteristics to those involved or identified as victims within a given type of experience or event that they might feel uncomfortable about or reject. Strobl and Shoham (2010) describe a process of how victimhood is constructed and how this identification of victims might not accord with those receiving this description. For those bereaved by assisted suicide, the person choosing to die but having to travel abroad was described as suffering from this situation and that this suffering needed challenging, implying that the person dying from an assisted suicide was a victim of the legal position in the UK that must be changed.

The contribution and influence of the media in representing private grief, can be powerful in reshaping both individual and community identities in ways that may encourage the commodification of a vicarious engagement by the wider society and not always lead to informed or balanced arguments (O'Leary, 2018). For those bereaved by assisted suicide, it might be challenging to join a social debate that requires a victim, as to be a victim, the person choosing the assisted suicide must be subject to a perceived injustice. Social narratives that require victims may also imply that by removing the injustice, the suffering of such victims will be cancelled out or prevented in the future. For those with a life-limiting illness this may be challenging and require a myriad of different responses depending in the type of illness, illness trajectory, symptomatology, and the individuals' circumstances, including economic, social and psychological factors (Jamieson and McEvoy, 2005). To consider the experience of people bereaved following assisted suicide, it is helpful to include a social perspective that acknowledges the ways in which both stigmatisation and victimology place a part in the social debate around assisted suicide in the UK.

7.7. The Dual Process Model Reviewed

For participants in this thesis their experiences and actions or activities involved in enabling and campaigning can be further explored by considering how these might tend towards either loss or restoration-orientated activity.

The capacity to oscillate or move between these two is seen as promoting resilient coping, with coping described as “a complex regulatory process of confrontation and avoidance” (Stroebe and Schut, 2016) where the bereaved are confronted with the realisation of the death and its implications, but also may seek, at times, to avoid the reality of the loss. This process has been observed as playing a part in ordinary grief reactions (Stroebe and Schut, 2010) but is also useful to describe complicated grief or more problematic grief (Stroebe and Schut, 2016). Having the capacity to experience loss-orientation but without opportunities to move into restoration-orientation activities can denote chronic grief (Shear et al., 2005). Alternatively, being able to function in restoration-orientation only, without the capacity to experience loss-orientation activities can denote absent or delayed grief (Bennett et al., 2010). The acknowledgement that different attachment styles result in differences in vulnerability to loss and bereavement offers an individual explanation of the experience of grief, and whilst this is noted, the position taken in this research includes the social context of grief, and that the revised dual process model (Stroebe and Schut, 2015) might also explain how distortions in the person’s capacity to grieve might come about in relation to the roles and relationships they cope with, in this case as while enabling the assisted suicide, and then afterwards as campaigners.

7.8. Applying the dual process model to anticipatory grief

In this chapter, I introduce the dual process model to consider anticipatory grief, suggesting it has a valuable contribution to understanding both pre and post death experiences for those caring for a person with a life limiting illness. This is the first use of the dual process model to understand the experience of carers before a death. Personal correspondence with the authors of the dual process model (Stroebe, 2021) has further clarified and refined the use of the model alongside the theory of enabling and campaigning (See Appendix I).

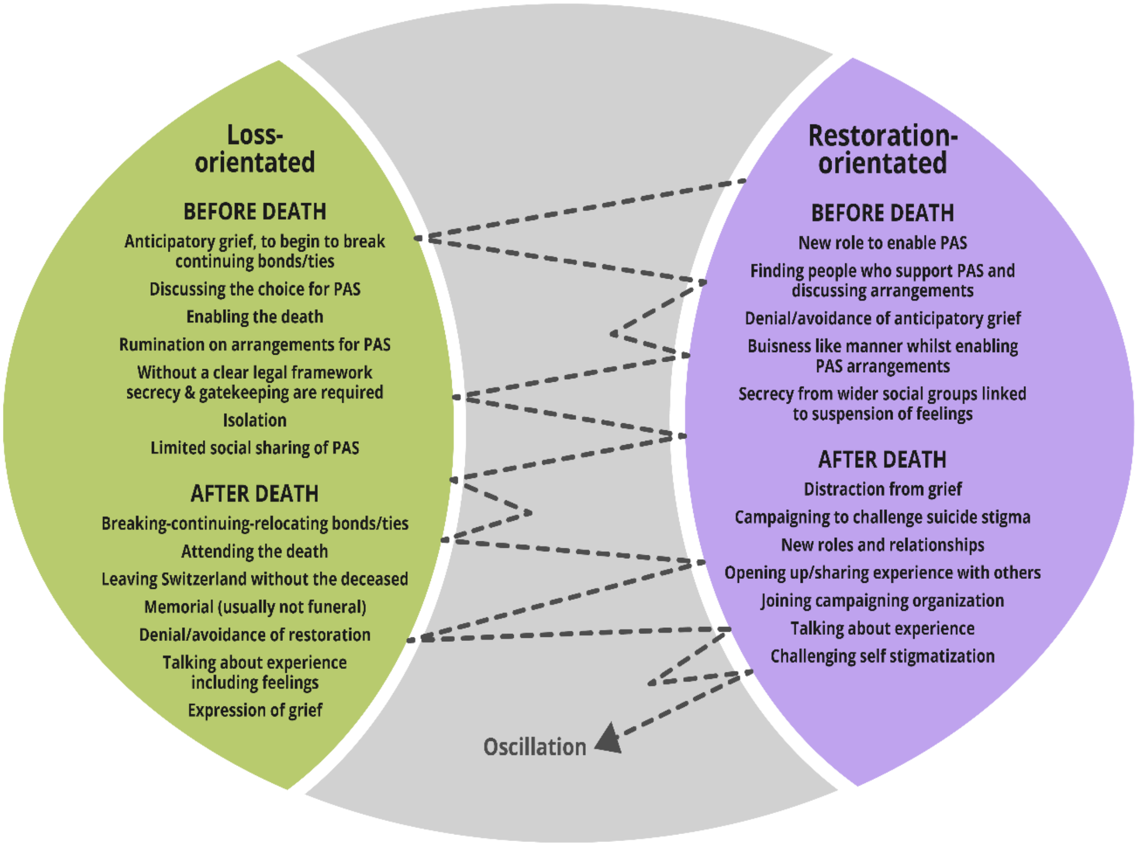


Figure 5. Experience of AS bereaved using loss and restoration-oriented approaches.

During the period before AS, my findings suggest that many of the activities required of family and friends are restoration-orientation activities. They demand that the person carrying out this role maintain a focus on the accomplishment of the AS, requiring them to have a business-like demeanour and to look to a current or future goal, rather than to consider what might be going to be lost, or to engage in anticipatory mourning. Loss-orientation activity before the death would be activity that operated to allow the expression of the future loss of the loved person.

The theory of enabling and campaigning can be usefully explored using the dual process model because this offers the theoretical capacity for balance between these experiences found in the grounded theory. The dynamic and changing movement between these experiences, can be usefully compared to the oscillations between loss and restoration that are proposed in the dual process model (Stroebe & Schut, 1999). Figure 3. demonstrates how these can be located as either loss-orientated or restoration-orientated activities, and how the bereaved are affected before death, by the experience of Enabling the Death and then After the Death, appear to engage in Campaigning as a part of their Restoration Oriented activity. See findings in Chapter 5.

The dual process model, developed from the stress coping model of Lazarus and Folkman (2001) can capture this co-occurrence of both emotional and problem-focused stressors, but it also enables the identification of both loss and restoration-oriented activity within grief and bereavement. By adding loss and restoration-orientation, the dual process model suggests there might be both emotional and problem-focused activity, and shows how during grief and bereavement there is the capacity to find an oscillation, balance or imbalance, between these. The enabling and campaigning grounded theory of this thesis highlights how the dual process model offers insight into the challenging and dynamic experience of carers before a death occurs.

The participants taking part in the research for this thesis, as close relatives, or friends of those experiencing assisted suicide, present accounts of the pre-bereavement experience of enabling, and the subsequent post-death campaigning activity as being highly important parts of their experience. The analysis of their accounts, using constructed grounded theory finds that they are linked and appear to have a similar dynamic pattern between enabling and campaigning, and that the enabling role taken before the death influences the ways in which grief may be expressed after the death; that there is an internal logic that draws the participants to react by taking part in the activities of campaigning.

This dynamic quality has been described in relation to affect, where the bereaved can show varying degrees of flexibility in their capacity to hold both negative and positive experiences independently, and to “self-regulate their affective experience independently from the broader stressor context” (Coifman et al., 2007) p.386). Stroebe and Schut (2010) describe the “waxing and waning” of grief as an “ongoing flexibility, over time” (p. 213), again stressing the need to understand the dynamic and everchanging quality of emotion in loss-oriented activity and the restoration-oriented adjustments to changes in the assumptive world (Janoff-Bulman, 1992) that enable the bereaved to move between these stressors.

7.8.1. The dual process model and the needs of carers before a death not due to AS

The dual process model offers the capacity to understand the dynamic patterns taking place as carers seek to manage the current responsibilities of their role before the death, but also describes how they might benefit from balance between these and possible loss-orientation activities, for example, considering what might be lost when the person has died. Further exploration of anticipatory grief using the dual process model to chart, measure and understand the relationship between loss and restoration-oriented activities for carers with a high level of practical responsibility would be valuable.

The individual tendencies for more or less flexibility between loss and restoration-orientation may be usefully applied alongside two influential approaches to supporting people who are grieving. Practitioners offering bereavement support from an attachment theory perspective (Parkes, 2010) and narrative approaches to understanding meaning-making (Neimeyer, 2012) contribute to therapeutic interventions for carers and have good theoretical fit with the dual process model (Stroebe, 2002) and (Stroebe and Schut, 2015).

7.9. The needs of people bereaved by AS

Within societies having a permissive legal framework, assisted suicide remains a complex issue that will and should continue to challenge society and individuals (Wright et al., 2021). Campaigning organisations (Dignity in Dying 2021b) give accounts of how the UK arrangements prevent open discussion, however, in Switzerland, a country with a legal framework there can remain a suicide stigma that continues to operate leading to gatekeeping and secrecy and less likelihood of taking up pre and post bereavement support (Gamondi, 2015) giving the findings of this study further relevance beyond the UK. The capacity to recognise and accept the ambivalent feelings arising for those involved in the care of those wishing to die in countries with or without a permissive legal framework, remains important to enable the improvement of end-of-life care (Gerson et al, 2020).

The findings from this study indicate great responsibility for those enabling AS and that these people may continue in isolation following the death, due to the social stigma that accompanies suicide and suicide bereavement. Long (2001) identifies that AS is a complex and challenging issue at both a societal and individual level and Richards and Krawczyk (2021), describing dying as a collective social process, suggest the campaign for assisted dying is “not so much a cause but rather a symptom of a cultural loss of meaning in the human experience of dying”.

Ho (2021), in a study of palliative and hospice care providers, in a region with a legal framework, recommends that education, training and debriefing for team members would enable better support for palliative care teams involved in enabling assisted suicide. Palliative and hospice care providers experienced some distress and moral ambiguity, as well as needing to manage the needs of the patient choosing MAiD, and sometimes the competing needs of carers and families. Gerson et al. (2020), following a literature review, recommend that palliative care physicians take a clearer role in developing practices around assisted dying as this has significant consequences for “the holistic care of people at the end of life but also for the overall discipline and philosophy of palliative care.” (Gerson et al., 2020, p.1300).

Palliative care professionals and organisations in the UK are challenged as they continue to consider and adapt to the changes in attitudes to assisted suicide and the legal changes across the world. Cecily Saunders’ (2006) concept of total pain, central to the philosophy of palliative care, considers how to reduce the patient’s psychological, social, and spiritual suffering as well as the physical symptoms of pain. When the medical model no longer felt able to cure a patient, the palliative care movement offered a challenge to the medical model of illness (Walter, 1994) and offered new ways to support the suffering of the dying. A study by Dees et al. (2011) finds that understanding suffering requires a framework that encompasses the psychosocial experiences of a patient. However, implicit with both is a view that suffering can be overcome and may even lead to psychological and spiritual growth with ‘purposeful suffering’ (Davies, 2011). Davies, (2011), suggests that ideas of ‘negative suffering’ are becoming more prevalent, associated with the secularisation and medicalisation of death and dying.

This potential for growth or ‘purposeful suffering’ (Davies, 2011) includes those who care for the dying, both family and friends and professionals. Kleinman (2009, p293), writing about offering end-of-life care to his wife, describes caring as “a moral practice that makes caregivers, and at times even the care-receivers, more present and thereby fully human.” Kleinman views caring for someone as they die as humanising, echoing the work by Kellehear (2015, p.122) from the perspective of the person that is dying, writing that “the reciprocity inherent in these circumstances commonly and logically promotes increasing love.”

Those considering changes in the law and the provision of AS need to be mindful of the needs of those bereaved (Srinivasan, 2019), as the needs of the dying person are usually given higher priority by medical staff, with little or no consideration of the needs of the enablers of these deaths (Gamondi, et al. 2019). Andriessen, et al. (2020) recommended addressing the needs of the family members as part of the arrangements for AS. Providing a space to discuss the choice for an assisted death, and the possible implications for the family as well as the person who will die would enable a more open dialogue (Dees et al., 2013) and lessen the experience of isolation and responsibility (Gamondi, 2015).

Tailored psychoeducational information and advice could be usefully created to support those bereaved by AS. Although there are limited specialist resources available for the bereaved in countries where there is a legal framework, there are limited new developments with this group of bereaved in mind. Beuthin, et al. (2021), in Canada where Medical Aid in Dying (MaID) is legal, make suggestions for the care of these bereaved. The recommendations for care during the planning of the death are seen to support later grief experience. They suggest having a certainty of death date, enabling a ‘countdown’, affording time to say goodbye and enacting the death as a ceremony. Also, family members are encouraged to engage in the planning which the authors suggest supports later sense-making (Beuthin et al., 2021).

Although carers may support the decision, they might struggle with the choice, grieving that this death occurred through MAiD. Ho (2021) makes further recommendation for bereavement support that is tailored to the needs of those bereaved in this particular way. Following an AS, there is no evidence of any research into the effectiveness of tailor-made support for those bereaved by AS although, as previously noted, there is a limited body of research about the experience and grief outcome for those bereaved in this way (Gamondi et al., 2018).

7.10 The needs of those bereaved by assisted suicide in the UK

As the legal situation in the UK continues to remain unclear, families and friends will continue to feel that they are unsure of how people in the wider society and organisations are able or willing to support them both before and after the death. The consequences of this lack of clarity are demonstrated in the findings and grounded theory within this thesis.

For those first enabling and then becoming bereaved by assisted suicide, the increased stress of coping with the many restoration-oriented challenges, is magnified by the social context of stigma and the legal uncertainty, and this serves to lessen the opportunity for the flexible 'waxing and waning' (Stroebe and Schut, 2010, p. 213) that would also allow loss orientated activity and encourage opportunities for anticipatory grief. The findings suggest that those tasked with the role of enabler of assisted suicide are expected to find loss-oriented activity more challenging and may benefit from pre-bereavement support that seeks to increase the potential flexibility of emotional expression alongside the coping with restoration activity. The social need to gatekeep and keep the planned death a secret can disable any loss-oriented discussion with other relatives or friends, including any opportunities to voice possible ambivalence they might have felt about the decision.

Cruse, a leading national UK-wide bereavement support service, makes no specific reference to deaths due to assisted deaths or suicide on their page for those bereaved by suicide (Cruse, 2021). The effect on the lives of these bereaved by assisted suicide in the UK, and ways they may negotiate their grief, require further exploration with a view to improving the development of support for people engaged in this challenging life experience.

7.11. Implications of a changed legal framework for assisted suicide in the UK

As the legal framework in the UK is revised and may become legal, those people bereaved by AS will continue to need support both during the arrangements for the AS and after the death. UK health and palliative care organisations that are currently hesitant in taking a stance in relation to assisted death may communicate to their staff, patients and carers that they are not open to discussion about AS, which functions as a form of censorship that limits any support for patient and family, both before and after the death (Fish, 2017; Gerson, 2019).

Following my exploration of the experience of those bereaved by assisted suicide I recommend the creation of targeted support by health and palliative care organisations, for those enabling AS.

The current hesitancy by UK health and palliative care organisations is also challenged by a study suggesting that patients welcome the opportunity to include discussion of a wish to hasten their death, for example, a study of patients with advanced cancer explored offering a proactive assessment (by healthcare staff) of the wish to hasten death. (Porta-Sales, 2019), finding a majority of patients (94.8%) did not find the assessment to be upsetting, and a majority of patients (79.3%) believed it is important to routinely evaluate this for patients in this position.

The experience of enabling is made more difficult within a social and legislative framework that is unclear such as in the UK (House of Lords Library, 2021 b), however ambiguity can exist in countries that have more clearly legalised forms of assisted dying. Legal ambiguities are still present in other countries with a clearer legal framework (Buchbinder et al., 2019) attributed this to the complexity of both social and ethical issues (ten Cate et al., 2017). In the UK the experience of enabling is made more difficult within a social debate that is polarised (Price et al., 2014), with many who support this choice, (Dignity in Dying, 2021a) suggesting that the professional specialisms of palliative care and hospice need to be able to discuss assisted suicide (Ganzini, et al. 2006).

Creating opportunities for more open dialogue would offer those enabling the assisted suicide the chance to speak more openly about their experience and the arrangements that need to be carried out, including expression of how onerous these can sometimes be. In the UK, this support is not readily available, in large part due to the lack of clarity about the legal position which leads to less opportunities to find someone who is able to discuss this in advance of the death and after the death in bereavement support (Dignity in Dying, 2021a).

Bereavement following AS is often a hidden experience and it is unknown how many UK bereaved may struggle on in this place of isolation (Fish, 2017). However as publicity of this option grows and if there is a change in the legal position (House of Lords Library, 2021 b), bereavement services and providers need to prepare to meet the unusual needs of these bereaved additionally and differently to those bereaved by other suicide bereavement.

By offering a valuable description of how those bereaved by AS manage both loss and restoration following a death, the dual process model conveys how the bereaved move towards the creation of meaning following these challenging life events as they work and rework both their experience of loss and their experience of new challenges and accomplishments. The important contribution of the dual process model is to offer insight into the regulation and coping required during grief, that encompasses balance and resilience, or imbalance and increased difficulties for the bereaved and it is recommended that this model continues to be explored as part of the development of support for these bereaved.

Chapter 8. Conclusion and contribution to knowledge

In this concluding section, the contribution of the theory of enabling and campaigning is reviewed with additional discussion of how the dual process model contibutes to understanding the experience of those bereaved by AS. There is consideration of the use of constructed grounded theory within this thesis and how reflexivity on the personal and professional experience of the researcher can be understood and contributes to the methodological rigour of this thesis (Charmaz, 2014). Finally the limitations of this thesis are reviewed and further consideration is given to recommendations for future research.

8.1. Enabling and Campaigning

This grounded theory makes a valuable contribution to understanding the unusual experience of those bereaved by AS. Carrying out a review on the experience of suicide bereavement has brought insight into the similarities with AS bereavement, particularly highlighting the actions of stigma and the social and interpersonal influences on the experience of those bereaved by suicide and AS. Applying the dual process model to my findings of the experience of those bereaved by assisted suicide, and to both before and after the death, has indicated a dynamic relationship between the restoration and loss-oriented activities both before the death and after the death.

8.2. The dual process model and pre bereavement experience

By comparing this theory with the dual process model I have demonstrated the valuable insight this model brings to the experience of carers, as well as specifically for those involved in caring and enabling AS. I have shown that the process of oscillation between loss and restoration-oriented activities can help to explain how grief and bereavement are experienced by these participants. This finding might also indicate the richness of this model in helping to understand the experience of caring for someone with a life-limiting illness, anticipatory grief and subsequent grief and bereavement.

This is the first time that the dual process model has been applied to pre-bereavement experience, including anticipatory grieving, enabling and loss as well as restoration-oriented activities that take place during the period after a life-limiting diagnosis is made and up to the death. (See Appendix I, Email correspondance with Stroebe M. S. & Schut, H. authors of the dual process model).

For these participants bereaved by AS there is a dynamic relationship between the experience of the circumstances of a death and the subsequent grief, and it is now possible to consider further research to extend this use of the dual process model to bereavement following other kinds of deaths where anticipatory grief is possible, for example when a life-limiting diagnosis is made.

8.3. Limitations and strengths of the study

The methodological framework chosen in this thesis, constructed grounded theory, enabled the researcher to connect the individual experience of participants. An alternative approach using interpretative phenomenological analysis (IPA) (Smith et al., 2009) was considered, however the significance of the intrapersonal and social within the experience of bereavement seemed more valuable and was chosen as offering the opportunity to best understand the needs of these bereaved. The choice of a constructed grounded methodology offered the capacity to capture the interpersonal and social dimensions of experience (Charmaz, 2014).

Using a constructed grounded theory approach and a limited number of participants, this thesis does not suggest that these qualitative findings are predictive, however that they can enrich and develop our understanding of those bereaved in this way and can inform the development of support for this group of people.

In this research the participants challenged stigma by becoming campaigners and this played a key part in their choice to become participants in this research, with all except two stating that they were motivated to take part by their wish to change the law. Within the current UK legal framework (House of Lords Library, 2021 b) the lack of clarity about the legal position is noted and recognised in this thesis as having an influence on participants' experience, including the likely effect of stigma. However this research can not be extended to cover the experience of people bereaved in this way who might not have been involved in the decision making and arrangements for the death.

There was no opportunity to consider the experience of those bereaved by assisted suicide who did not know about the death until afterwards. Despite efforts to recruit them (See Section 4.3. Recruitment), participants who had not been involved in enabling the assisted suicide, did not come forward and this was a considerable limitation. It is expected that these bereaved would have a vastly different experience and that the theory of enabling and campaigning would not directly give opportunities to consider their needs.

There is a need to develop the recruitment of family members and friends who have not been involved in the arrangements for the death and explore how their experience may differ and how they might have additional support needs, for example, similarities in affect to those bereaved by sudden or unexpected deaths.

8.4. Recommendations for clinical practice and future research

Recommendations are made for further research and to develop understanding of the special and additional needs of those involved in enabling assisted suicide or bereaved by assisted suicide. There has been limited research into the experience of being bereaved by an assisted suicide, (Fish, 2017) and with a growing number of countries legalising assisted dying, there continues to be less consideration of the needs of or implications for bereaved relatives (Variath, 2020). There continues to be a focus on the needs and experience of the person choosing the AS (Ten Cate et al., 2017) and also of the impact on the professionals involved in arranging an assisted suicide, for example Wright (2021).

Participants, despite knowing about the death in advance, appeared to have had reduced opportunities for anticipatory grief due to their role as enablers of the death. It is recommended that further research is designed to consider the opportunities for anticipatory grieving of these bereaved and how to support positive experiences for this aspect of their caring role, for example an intervention study. The dynamic relationship between the role of enabler of the death and future meaning-making might be informed using the dual process model to consider how best to support those managing the arrangements taking place before AS.

Recommendations are also made to support further exploration of the dual process model and its application to pre bereavement experience, for example carers of those with life-limiting illness.

8.4.1. Those not included in the decision making and arrangements for AS

Further research for those bereaved by assisted suicide but not involved in the decision making or enabling of the death would be valuable. It was only possible to recruit two of my participants that were not involved in the decision making and arrangements for the death and they were not close friends or family of the deceased. It is strongly recommended that people who have been bereaved by the death of a relative due to AS, and were not included in the decision making or arrangements for AS, be sought for further exploration. Recommendations are made to consider the different needs of those bereaved by AS but excluded from the decision-making, role of enabling and not being aware of the plan until after the death.

As it was not possible to recruit many people excluded from the decision -making process by the dying person, and who did not find out about death until after the event, losing the opportunity to say goodbye, it is not possible to consider what other different or special support needs they might have, however the review (Chapter 5) about the needs of those bereaved by suicide might give some indication. The experience of those closely related to someone choosing AS, but excluding them from prior knowledge of their death, may result in limited opportunities for these relatives for anticipatory grief and they might experience some of the issues associated with those bereaved by suicide.

It is noted that it was extremely difficult to get access to these relatives and friends and this might point to the smaller number of people in the UK experiencing bereavement by AS, however it may also point to the continued stigma and secrecy surrounding suicide, particularly the possible impact when someone close to you has not confided in you or trusted you with this information before they died.

8.5. My position in the research process and use of reflexivity

The methodological stance within this thesis is constructed grounded theory. As a researcher I take the view that the knowledge created in this thesis is co-constructed between myself and the participants. Charmaz (2014) describes a constructed grounded theory approach to method and methodology, enabling a creative generation of theory, grounded in the research data but also acknowledging the role of the researcher both personally and professionally. Reflexivity is an important methodological tool, enabling the researcher to closely examine their influence on the data analysis and production of theory. For example, using memos during the analysis of interviews, the literature and throughout the writing process.

As a bereavement counsellor my career has centred around the care of those bereaved both as a therapist but also as a manager of bereavement services. This has influenced me to have an ongoing focus on the therapeutic usefulness of the theory created from this study. Acknowledging this focus has enabled the direction and choice of existing literature in the Discussion chapter, that has been used to further explore the findings. For example, the dual process model (Stroebe and Schut, 2010) is a well known and effective tool for enabling the care of the bereaved providing a space for the exploration of balance between the needs of those bereaved to both grieve and to come away from grief (Stroebe et al., 2013). I acknowledge that the choice of this model comes from a therapeutic focus that hopes to enable better understanding and the practical application of this understanding to develop suppport for those bereaved by AS.

I have also acknowledged that personal circumstances affect my construction of the data and findings, for example, having worked in a hospice based counselling service, and being influenced by a palliative care approach (Carolan et al., 2015). The palliative care movement, influenced by practitioners and writers such as Cecily Saunders (Clark, 2018) and Colin Murray Parkes (Kerslake, 2020) assume that death is more than a physical process, and stresses a concern for the emotional, social and philosophical dimensions of death, dying and bereavement. Hospice and hospital-based palliative care considers how our death or the deaths of those we love, whilst presenting the ultimate challenge to each of us, also enables the opportunity for experiencing the ultimate experience of what life and love means to us (Clarke, 2020). This philosophical stance has become part of my personal life journey and meaning-making, embodied in the deaths of my own parents, where one was over-medicalised and swift; where the other, though painful, over a prolonged period and challenging for all involved, has become an important part of what the deceased person was to their family and friends.

The palliative care movement has provided opportunities for health care to consider a holistic approach to the life experience of death and bereavement, in a way that many specialisms of health care seem less able to value. Rather than staying within a medical model of diagnosis and quantitative evidence (for example in relation to pain relief), palliative care is also concerned with the experience of the dying person, their family and friends (for example, the spiritual pain of the deceased or the bereaved) and the choice of a qualitative methodology for this thesis relates to the paradigm most valued by this researcher when addressing the experience of those bereaved in this way.

8.6. Final thoughts

These findings give insight into the experiences, roles and actions taken by the bereaved, within the process of enabling AS. They describe actions and roles taken by those bereaved by AS that takes place in another country. The findings reflect the current legal and socio-cultural setting for AS in the UK, a country without a clear legal framework and consider how this affects the bereaved.

The findings have enabled the development of a constructed grounded theory of the experience of those bereaved in the UK following AS and suggest a dynamic relationship between the roles of enabler of AS and campaigner for AS. It appears that there was a compensatory relationship between the need to be secret due to stigma before the death and the resulting motivation to become campaigners. This has developed a dynamic and oscillating theory of enabling and campaigning, describing helpful and less helpful processes of grief for those bereaved by AS, contributing to the understanding and care of these bereaved.

The findings and theory in this study about the experience of those bereaved by AS have led to the first exploration of anticipatory grief and the dual process model. This use of the dual process model indicates its potential to understand the experience of people caring for those with a life-limiting illness.

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Appendix A a

Invitation email

From: Fish, Janette <j.fish@lancaster.ac.uk>
Sent: 27 January 2017
Subject: Research exploring the experience of bereavement following an assisted death

Dear

I am a PhD student at Lancaster University in the Faculty of Health and Medicine.
I understand from your work in this area that you have an interest in death and dying and bereavement.
You have been approached because you may know of people living in the UK who have experienced the death of a family member or friend, following a physician assisted death in a country that has a legal framework to support that death (such as Switzerland, Holland or Belgium.)
There is very little known and no specific research about the needs of people bereaved in this way and as the numbers affected grow it is important for us to find out what they might be experiencing and what they might need.
If you know someone who might like to tell me about their experience, please can you pass on this email or give them my contact details. Or if you work for an organisation that might be able help publicise my call out for participants, I would be very pleased to hear from you. I am happy to send you some leaflets to circulate at any conferences or events that you might be organising or attending. Many of my participants have been friends or family of members of university staff who have seen my leaflets on staff notice boards.
I include attachments that I am sending to people who might be interested in taking part. This includes participant information which explains the sorts of situations they might have experienced that I am hoping to include in this research project.
If you have any other enquiries or would like to tell me about your own experience, then please get in contact by emailing me on j.fish@lancaster.ac.uk.
I look forward to hearing from you. You are also welcome to phone me with any questions you might have.
Jan Fish
PhD Student University of Lancaster
Website www.bereavementresearch.wordpress.com

Appendix A b
Invitation Flyer

Has someone close to you travelled to Switzerland* to end their life?

CALL FOR RESEARCH PARTICIPANTS

Would you like to help us to understand how this has affected you?

This research is exploring how a physician assisted death affects the bereaved.

If you would like to participate and find out more information about this research project please contact me via email:

j.fish@lancaster.ac.uk

I look forward to hearing from you
Janette Fish

PhD Student, University of Lancaster

If you know someone who may be interested in participating please pass this invitation on

www.bereavementresearch.wordpress.com

*(other countries that have a legal framework to support this kind of death are Holland and Belgium)

Appendix B

Participant Information Sheet

Participant Information with Expression of Interest Form

Participant Information Sheet

How does assisted dying affect the experience of the bereaved in the UK?

My name is Jan Fish and I am conducting this research as a student in the PhD Palliative Care programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore the experience of the bereaved who have had a family member or friend end their life with a physician assisted death. As the number of people in the UK who seek assisted suicide grows, these UK nationals often travel to Dignitas or Lifecircle, clinics in Switzerland that enable physician assisted suicide or deaths.

There is no research about the experience or possible effect on the bereaved family members from the UK whose family or friends choose to end their lives in this way.

This study seeks to interview up to 25 participants to give insight to the experience and needs of those bereaved in the UK, by physician assisted death. The recorded interviews will be analysed and the findings will be form a PhD study at the Lancaster University (Palliative Care).

Why have I been approached?

This study hopes to find out about how bereaved people experience the death of a friend or relative who has died following a physician assisted death. This needs to have taken place in a country that has a legal framework to allow a physician assisted death or suicide, such as Switzerland, Holland or Belgium.

You also need to be over 18, male or female, and living in the UK and your bereavement has taken place more than six months before the date of your research interview.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part and if you decide to go ahead and then wish to withdraw this is possible up to the point in the research when the findings begin to be analysed by the researcher by which time it would then be difficult to remove your information.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to meet for an interview with the researcher which would last up to one and half hours at a location that you can easily travel to, or at your home. The interview will be an opportunity to share your experience of bereavement. It is also possible to arrange for the interview to take place by Skype, although complete protection of the interview cannot be ensured by the researcher as there is some risk of data relayed by Skype, being accessible by others.

Will my data be Identifiable?

The information you provide is confidential. The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.
- Hard copies of questionnaires will be kept in a locked cabinet.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- At the end of the study, hard copies of questionnaires will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.

- The typed version of your interview will be made anonymous by removing any identifying information including your name. Direct quotations from your interview may be used in the reports or publications from the study, but your name will not be attached to them and any facts that might identify you would be removed, for example any reference to which clinic or the date that a trip was made, or any other fact about circumstances that might allow someone to work out who is being discussed.
- All your personal data will be confidential and will be kept separately from your interview responses and will not appear anywhere in the document.

There are some limits to confidentiality, for example if for example you told me in the interview that you, or someone else, was at significant risk of harm. Then I will have to break confidentiality and speak to my supervisors about this and then might need to speak to someone else to ensure your or another persons safety. If possible, I will tell you if I have to do this. See appendix for a description of the current legal position in England and Wales.

What will happen to the results?

While the research is being carried out I will be speaking to my academic supervisor who guides me during my studies. The supervisor/s will also preserve confidentiality in the same way that I will. The results will be summarised and reported in a dissertation/thesis and may be submitted for publication in an academic or professional journal. Again any information used from the interview with you will be made anonymous.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided on the debriefing sheet that you will be given at the interview.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it? If you have any questions about the study, please contact the main researcher: Jan Fish - j.fish@lancaster.ac.uk I will be contactable on this email address.

Or email the research supervisor Nancy Preston - n.preston@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact the Research Director for Health Research.

Title: Professor Steven Jones
Email: s.jones@lancaster.ac.uk
Health Research Division Lancaster
University Lancaster

LA1 4YG

If you wish to speak to someone outside of this Doctorate Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk Faculty of
Health and Medicine

(Division of Biomedical and Life Sciences) Lancaster
University

Lancaster LA1
4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or

in the future, the following resources may be of assistance. Cruse Bereavement Care Helpline on **0844 477 9400**

The Samaritans helpline on **08457 90 90 90**

Appendix describing current legal position in England and Wales

Following a public consultation exercise in 2009, the then Director of Public Prosecution, Keir Starmer, QC, published a policy provides guidance to prosecutors on the public interest factors to take into account in reaching decisions in cases of encouraging or assisting suicide following a death by assisted suicide. This is called Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide, published in February 2010, and updated October 2014. (Crown Prosecution Service, 2010).

Although the Suicide Act (1961) is still in place, prosecution of those who are aware of or assist to some degree in a physician assisted suicide that takes place will only take place in the event that there is sufficient evidence AND a prosecution is required in the public interest.

There are two sets of public interest factors to be taken into account, the first set which tend in favour of prosecution and a second set which would suggest that a prosecution is not in the public interest.

A prosecution is more likely to be required if:

- the victim was under 18 years of age;
- the victim did not have the capacity (as defined by the Mental Capacity Act 2005) to reach an informed decision to commit suicide;
- the victim had not reached a voluntary, clear, settled and informed decision to commit suicide;
- the victim had not clearly and unequivocally communicated his or her decision to commit suicide to the suspect;

- the victim did not seek the encouragement or assistance of the suspect personally or on his or her own initiative;
- the suspect was not wholly motivated by compassion; for example, the suspect was motivated by the prospect that he or she or a person closely connected to him or her stood to gain in some way from the death of the victim;
- the suspect pressured the victim to commit suicide;
- the suspect did not take reasonable steps to ensure that any other person had not pressured the victim to commit suicide;
- the suspect had a history of violence or abuse against the victim;
- the victim was physically able to undertake the act that constituted the assistance him or herself;
- the suspect was unknown to the victim and encouraged or assisted the victim to commit or attempt to commit suicide by providing specific information via, for example, a website or publication;
- the suspect gave encouragement or assistance to more than one victim who were not known to each other;
- the suspect was paid by the victim or those close to the victim for his or her encouragement or assistance;
- the suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional, a professional carer [whether for payment or not], or as a person in authority, such as a prison officer, and the victim was in his or her care;
- the suspect was aware that the victim intended to commit suicide in a public place where it was reasonable to think that members of the public may be present;
- the suspect was acting in his or her capacity as a person involved in the management or as an employee (whether for payment or not) of an organisation or group, a purpose of which is to provide a physical environment (whether for payment or not) in which to allow another to commit suicide.

On the question of whether a person stood to gain, (paragraph 43(6)), the police and the reviewing prosecutor should adopt a common sense approach. It is possible that the suspect may gain some benefit - financial or otherwise - from the resultant suicide of the victim after his or her act of encouragement or assistance. The critical element is the motive behind the suspect's act.

If it is shown that compassion was the only driving force behind his or her actions, the fact that the suspect may have gained some benefit will not usually be treated as a factor tending in favour of prosecution. However, each case must be considered on its own merits and on its own facts.

The factors in favour of not prosecuting are listed below:

- the victim had reached a voluntary, clear, settled and informed decision to commit suicide;
- the suspect was wholly motivated by compassion;
- the actions of the suspect, although sufficient to come within the definition of the offence, were of only minor encouragement or assistance;
- the suspect had sought to dissuade the victim from taking the course of action which resulted in his or her suicide;
- the actions of the suspect may be characterised as reluctant encouragement or assistance in the face of a determined wish on the part of the victim to commit suicide;
- the suspect reported the victim's suicide to the police and fully assisted them in their enquiries into the circumstances of the suicide or the attempt and his or her part in providing encouragement or assistance.

Further information detailing the law can be found on the Crown Prosecution Service website on http://www.cps.gov.uk/publications/prosecution/assisted_suicide.html

and http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html

September 2016
j.fish@lancaster.ac.uk

Appendix C

Consent form and debriefing information

Consent Form

Research Proposal

Title

How does assisted dying affect the experience of the bereaved in the UK?

Researcher's name

Jan Fish

We are asking if you would like to take part in a research project which is interested in finding out about the experience of bereaved people who have had a close friend or family member die following a physician assisted death. Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Jan Fish.

Please initial each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be kept until the research project has been examined. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐
7. I understand that the research may be published in journals or other publications. ☐
8. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with her research supervisor. ☐
10. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐
11. I consent to take part in the above study. ☐

Name of Participant_______________________
Signature__________________________ Date ______________

Debriefing information

Information for you after your interview.

Thank you for meeting with me today. This information is to tell you about some of the ways people might feel after meeting to talk about their bereavement and how you might find support if you need to.

Sometimes talking about things can provide some relief, although it can also make you feel that some of the feelings you talk about might be more present. As this can be tiring and sometimes stressful, it can help to find ways of looking after yourself this evening and over the next few days.

Suggestions are:

find a way to care for yourself

treat yourself to something that might make you feel better

meet with people you like to be with at the moment

have an event you can look forward to

If you feel that these sorts of suggestions are not enough and you feel more upset that you usually do you might wish to:

contact someone you trust that you can talk to

contact one of the national or local bereavement services listed below

If you feel that you are at any risk and need medical or specialist support with your reactions

please call your GP and explain it is urgent

or contact the Samaritans who are able to take calls 24 hours a day to talk

Contact Information

Nationally

Cruse Bereavement Care Helpline on 0844 477 9400

Samaritans on 08457 90 90 90

Local Bereavement Service - phone the Cruse Bereavement Care Helpline and ask for details

Jan Fish is available by email on j.fish@lancaster.ac.uk.

Emails will be responded to within two working days unless there is an out of hours message explaining that I am not available.

Local Help

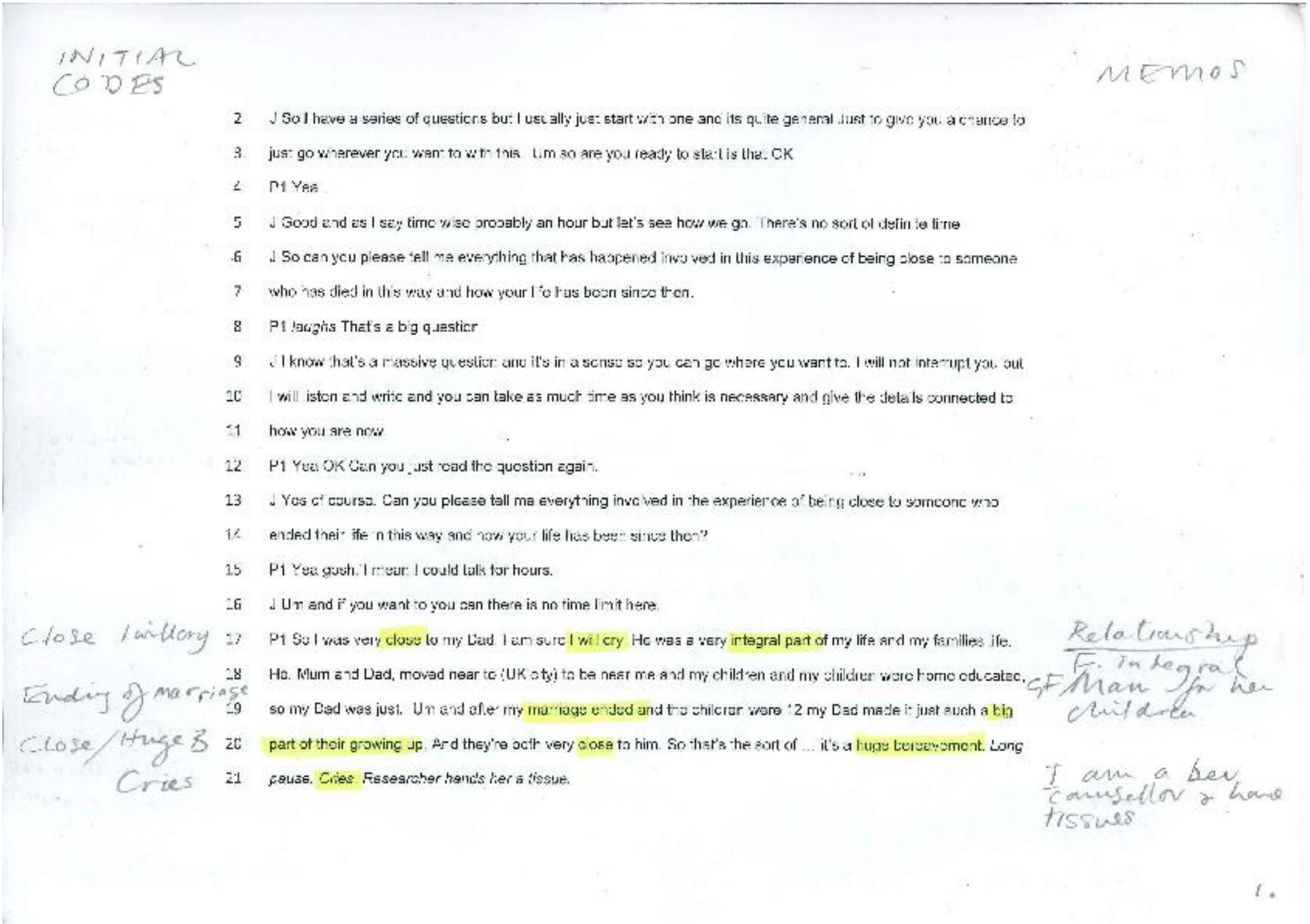
Ask Cruse Bereavement Care Helpline about your local bereavement service.

Contact your GP

Appendix D

Initial Coding

Example of coding with commentary



INITIAL CODES

MEMOS

J So I have a series of questions but I usually just start with one and its quite general just to give you a chance to just go wherever you want to with this. Um so are you ready to start is that OK

P1 Yea.

J Good and as I say time wise probably an hour but let's see how we go. There's no sort of definite time

J So can you please tell me everything that has happened involved in this experience of being close to someone who has died in this way and how your life has been since then.

P1 *laughs* That's a big question

J I know that's a massive question and it's in a sense so you can go where you want to. I will not interrupt you but I will listen and write and you can take as much time as you think is necessary and give the details connected to how you are now

P1 Yea OK Can you just read the question again.

J Yes of course. Can you please tell me everything involved in the experience of being close to someone who ended their life in this way and how your life has been since then?

P1 Yea gosh. I mean I could talk for hours.

J Um and if you want to you can there is no time limit here.

P1 So I was very close to my Dad. I am sure I will cry. He was a very integral part of my life and my families life. He, Mum and Dad, moved near to (UK city) to be near me and my children and my children were home educated, so my Dad was just. Um and after my marriage ended and the children were 12 my Dad made it just such a big part of their growing up. And they're both very close to him. So that's the sort of ... it's a huge bereavement. *Long pause. Cries. Researcher hands her a tissue.*

Close familiary

Ending of marriage

Close / Huge B

Cries

Relationship

F. Integral

SF Man for her children

I am a bev counsellor & have tissues

1.

Jan Fish Transcript P 1

Notes from initial coding

I have tried to make a line by line coding. See highlighted in yellow with pencil coding to left and memos to the right. This has been more time consuming than I had expected!

I have also marked a number of Invivo codes which I list below with Memos.

I have a couple of general points to make:

By using memos I have been finding patterns in how the Participant seems to be viewing me and what my views or judgements might be.

I have called these Participant -> Researcher (P -> R) So far I take this to include all aspects of how I think the Participant is changing (both consciously and unconsciously) their dialogue in relation to what they think I 'should' hear. This might be revealing what they feel is sensitive and might influence some aspect of the social debate or it might be that they need to deny this to themselves to some degree. (As a psychotherapist I have theoretical ideas about how/for what reasons people need to deny or keep something out of consciousness (as well as about grief) – and I will be thinking about how I bring these ideas that as part of my reflexivity)

This has led me to consider how many of my participants have been primarily motivated to participate by their need to contribute to legal change in the UK.

This leads me to wonder if I should ask more directly about this although all of the Ps so far have told me about their views on changing the law. This is not always in the interview but has been implicit in how I have made contact with them. ? I should probably ask about this more directly towards the end of the interviews or find other ways of recording this as part of the exploration of motivation?

Codes

Line 23	I understood why	P -> R she wants me to know that she understood why he chose an assisted death.
Line 31	knowing he was going	How the time before he died was changed by them knowing he was going. Lots of descriptions of how this was a special time. See also Line 32 amazing time - what the summer meant before he travelled to Dignitas.
Line 86	he just left	I felt that this was full of feeling and needed marking in some way
Line 151	aware of my own mortality	comes up later on lines 331 - 359
Line 151	not frightened of death anymore	as above
Line 238	secrecy and isolation	Talked about by all my participants.

Appendix E
Example of focused coding and categories

Concepts

Anticipated and feared death

Honouring wishes of deceased

Enabling the PAS

Accompanying and witnessing

Revealing the death

Campaigning

Experiences

Anxiety to avoid and fear about anticipated death

Isolation/Responsibility

Suppression of sadness and opportunities for anticipatory grief

Anxiety about legal process

Seeking advice from others with similar experience

Business-like

Anxiety – prevention of PAS

Controlling information

Isolation

Distress and anxiety

Painful journey

Responsibility/Isolation

Surreal experience
Anxiety of return to UK/legal sanction

Opening up

Burden of telling others and their reactions

Opening up about experiences

Seeking support from others with similar experience

Public expressions of experience

Processes

Protection of the deceased
Stigmatisation

Maintaining suppression of feeling
Memorialisation

Relinquishing suppression of fact of PAS

Relinquishing suppression of feelings about PAS experiences

Making meaning linked to changing law

Challenging stigma of suicide

Time and events experienced as part of PAS	Concepts	Experiences	Processes
DECISION FOR PAS	Anticipated death	Anxiety to avoid and fear about anticipated death Isolation/Responsibility Suppression of sadness and opportunities for anticipatory grief	Protection of the deceased
MAKING ARRANGEMENTS	Honouring wishes of deceased	Anxiety about legal process Seeking advice from others with similar experience Business-like	Stigmatisation
GETTING APPROVAL	Enabling the PAS	Anxiety – prevention of PAS Controlling information Isolation	Stigmatisation
THE DEATH	Accompanying and witnessing	Distress and anxiety	Maintaining suppression of feeling

		Painful journey **Responsibility/Isolation** **Surreal experience**	
AFTER THE DEATH	Revealing the death	**Anxiety of return to UK/legal sanction** **Opening up** **Burden of telling others and their reactions**	**Memorialisation** **Relinquishing suppression** of fact of PAS **Relinquishing suppression** of feelings about PAS experiences
GRIEF & MEANING MAKING	Campaigning	**Opening up about experiences** **Seeking support from others with similar experience** **Public expressions of experience**	**Making meaning linked to changing law** **Challenging stigma of suicide**

Appendix F

Example of reflective memo

Project: Bereavement following AS

Report created by jan on 02/09/2019

Memo Report

Selected memos (2)

Reflexivity

Feelings that arise from being Campaigned to. Participants are trying to persuade me

Finding out if I am in the camp that agrees with them or not.

If I come from a Palliative Care setting/university course I am judged not to be on their side/wariness of me.

Relationship to Interviewer

Participants motivation is largely due to personal commitment to campaigning

CAMPAIGNING

This will influence what the participant may choose to discuss - this may be largely unconscious - particularly as this is such a charged situation with legal and social taboos that the Participants may feel highly inhibited

This may limit expression of any aspects of the death that are not positive

The researcher has noted that the absence of any ambivalence about the death is notable (NEEDS FURTHER READING) AMBIVALENCE AND NORMAL GRIEVING

SOCIAL ISOLATION

Also Participants may feel relief at being able to express some of the feelings/events they have experienced.

Being a Campaigner also negates feelings of isolation.

Participants may feel isolated.

e.g." people dont really talk to me about it" "its quite nice actually to come here today"

Appendix G
Example of methodological memo

Project: Bereavement Following AS

Report created by jan on 03/08/2019

Memo Report

Selected memos (10)

Bereavement Experience of Participants

Dimensions of Grief will inform my thinking about these Ps and their grief.

for example the relationship to the deceased - what kind of relationship was this?

What might it have been like to be close to someone like this?

What functions in the relationship did the P have to undertake for the deceased in relation to their AS? i.e. they needed to do this for them.

There can be (normally) some ambivalence to anyone that we love. How is the ambivalence expressed?

Could the P have denied them their choice to die in this way?

Being the ENABLER of the death

RESPONSIBILITY for

1. arranging

2. going there with them

3. telling others

" I phoned up and booked this day, umm. and she was much happier then, much happier"

LEGAL POSITION

"malicious assistance"

"compassionate assistance" what is the distinction between these.

FEELINGS THAT SEEM APPARENT THOUGH NOT DIRECTLY EXPRESSED

Anger

Guilt

Overwhelmed with responsibility

Coping with grief so that can cope with practical issues.

Holding back grief until after the death.

Coding Memo - Time vs Timing

So there's something important in this about differentiating time (as periods etc) from timing (as an active choice) etc. etc.

Decision to have AS

Decision to have a AS appears to have three identified components so far:

Imagined Death

Illness and symptoms/affects of Illness

Character of Deceased

Events leading up to death

Administration

Assessment by Organisation

Booking arranging travel

Communication ready to send to those who do not know

Travelling with deceased

The last supper

Saying goodbye

Travelling to Dignitas

The death

Just after death

Disposal of body

Travelling back

---

participants are all members of Dignity in Dying

11/06/2019 14:49This causes me some concern as these members are already very pro AS and may be unlikely to have experienced (or to share) any ambivalence about AS

Process of Arranging AS

Process of Arranging AS appears to have following components

Illness - Diagnosis - Palliative Condition + Character of Deceased

Discussion with medical professionals (often reported as not possible)

leading to

Exploration of possible routes to AS - internet + organisations + people acting as mentors

Contacting Organisation

Deciding who Knows about AS (Sometimes family members/friends will exclude themselves)

Who is excluded from Knowing about AS

Assessment

Green Light

Timing of travelling for AS

Project Diary

Ctrl + D to time stamp

Appendix H.
Example of Theoretical sampling

Project: Bereavement Following PAS

Report created by jan on 12/04/2019

Code Report – Theoretical sampling

Initial coding supporting decision to add question to all subsequent interviews:

“If you had not agreed with their decision to have an assisted suicide, what would have happened?”

These coding’s support the character and beliefs of the deceased and the participants belief that they would seek out a suicide even if they disagreed with the decision for a physician assisted suicide.

○ If Bereaved Had Disagreed with Decision

1 Quotations:

4:75 J. Hmm or if you'd both said we don't agree with it, we don't want you…… (48906:49100) - D 4: Transcript P 5

J. Hmm or if you'd both said we don't agree with it, we don't want you to die this way?

P5. Umm / well she wouldn't have told us in the first place.

J. So you think she'd sort of checked you out.

2 Codes:

○ If Bereaved Had Disagreed with Decision / ○ she wouldn’t have told us

---

○ Bereaved decision to choose PAD

1 Quotations:

5:9 Anyway, she slept it off. She woke up the next day and she'd slept it…… (9343:9772) - D 5: Transcript P 4

Anyway, she slept it off. She woke up the next day and she'd slept it off and while she was asleep I thought, when she comes around, I want her to have an alternative. I don't want her to throw herself under a bus or a train or do something or cut / slash her wrists because she's absolutely determined to die, so I phoned up Dignitas, because I'd heard about it, I think, from her and I spoke to this very German doctor and he

2 Codes:

○ Bereaved decision to choose PAD / ○ First contact with Dignitas

Appendix I

Correspondence with authors (M Stroebe and H Schut) dual process model

08 October 2021

Dear Jan,

Thank you for your email. We are of course pleased that you find the DPM useful and appreciate your application of the model to bereavement reactions following AS. What an important and critical topic, it's great that you address these complex issues and draw attention to the unique manifestations with which this type of bereavement is associated.

As you will have realized, we are not experts at grounded theory approaches and cannot comment more broadly - nor do you expect that, I think. But more narrowly, your use of the DPM seems fine in general and it's very interesting to see your extension to pre-bereavement anticipatory processes. That is actually new (at least, I cannot think off hand of anyone else extending it to pre-loss - Henk will comment if he knows differently ☺) - so make the most of that uniqueness in your write-up! It makes a great deal of sense to highlight how the coping process begins beforehand, particularly under AS circumstances and the DPM seems as applicable before as after the death.

I just have a couple of details - and I reply for Henk too:

You indicate emotion focused coping on the LO side and problem focused on the RO side. We don't consider EF and PF equivalent to LO and RO. For example, one can have emotion focused reactions / coping strategies about the secondary stressors - feeling anxiety because one cannot manage the tasks that the deceased spouse had dealt with; or: one has to be problem focused in dealing with LO matters such as arranging the funeral. Does that make sense to you and tally with what your research has shown?

Regarding the details within each sphere, maybe a bit more nuancing here and there would help readers:

LO always has to do with the loss, so secrecy of feelings would be about the deceased more specifically and not secrecy about secondary stressors (like not wanting to admit incompetence in dealing with lawyers, finances, etc.). It would be good to be clear about that - maybe you already do so in your descriptive text. Also, you focus in the "after death" description on bonds - whereas it might be good to extend specification, for example, to processing memories, going over events before, during and after the death.

Regarding RO - again it's important to keep secondary stressors that come about as an indirect result of the death in mind. So sometimes what you mention could also be LO, for example, coping with anticipatory grief (but coping in advance with changes would be RO oriented). Similarly, opening up, sharing experiences could be LO sometimes as well as RO, depending on the content of what is shared.

I hope this all makes sense and is clear. Feel free to ask if not. And please do share your thesis with us - naturally in due course, we realize you are still busy writing it up.

All the very best for that, good luck and enjoy the process.

Best wishes,
Henka and Maggie

Appendix J a Development of a Process Model to identify key issues from findings

Social Context

Little support from UK **Prof Orgs**

Discussion in **inhibited**

Legal framework in UK

Information is **controlled**

due to anxiety and secrecy

Polarized debate

links with suppression of any doubt on both sides of argument

Support from campaigning orgs

Individual

Role as Enabler of AS negotiation between social and PcPAS – To manage and contain

Relationship with deceased

Love and wish to care for the deceased

The person choosing PAS needs them to carry out their wishes in a business like way to meet their needs

Any doubts or ambivalence about the decision is hard to express

Attachment style is controlled? May need them to be less emotional

Suspension of grief or 'affect' Effect on the experience of bereaved because they need to get on with the process and protect the deceased from the pain of the symptoms and the fear of dying without control
The fear of **the imagined death.**

Suppression of doubts or ambivalence toward deceased/decision

Effect on the experience of bereaved because they are in a relationship with a challenging person in a challenging circumstance and faced with a challenging decision to carry forward and they need to suppress ambivalence in case this is misunderstood as being someone who wants the death to happen because it is painful to bear the current experience of illness and suffering

Isolation

Effect on the experience of bereaved due to the **secrecy** involved in arranging PAS and the **taboo of suicide**

Making sense of experience

Meaning making after the death

Dealing with grief & emotions **Identity of Bereaved**

Toleration of doubt or ambivalence is likely to be low

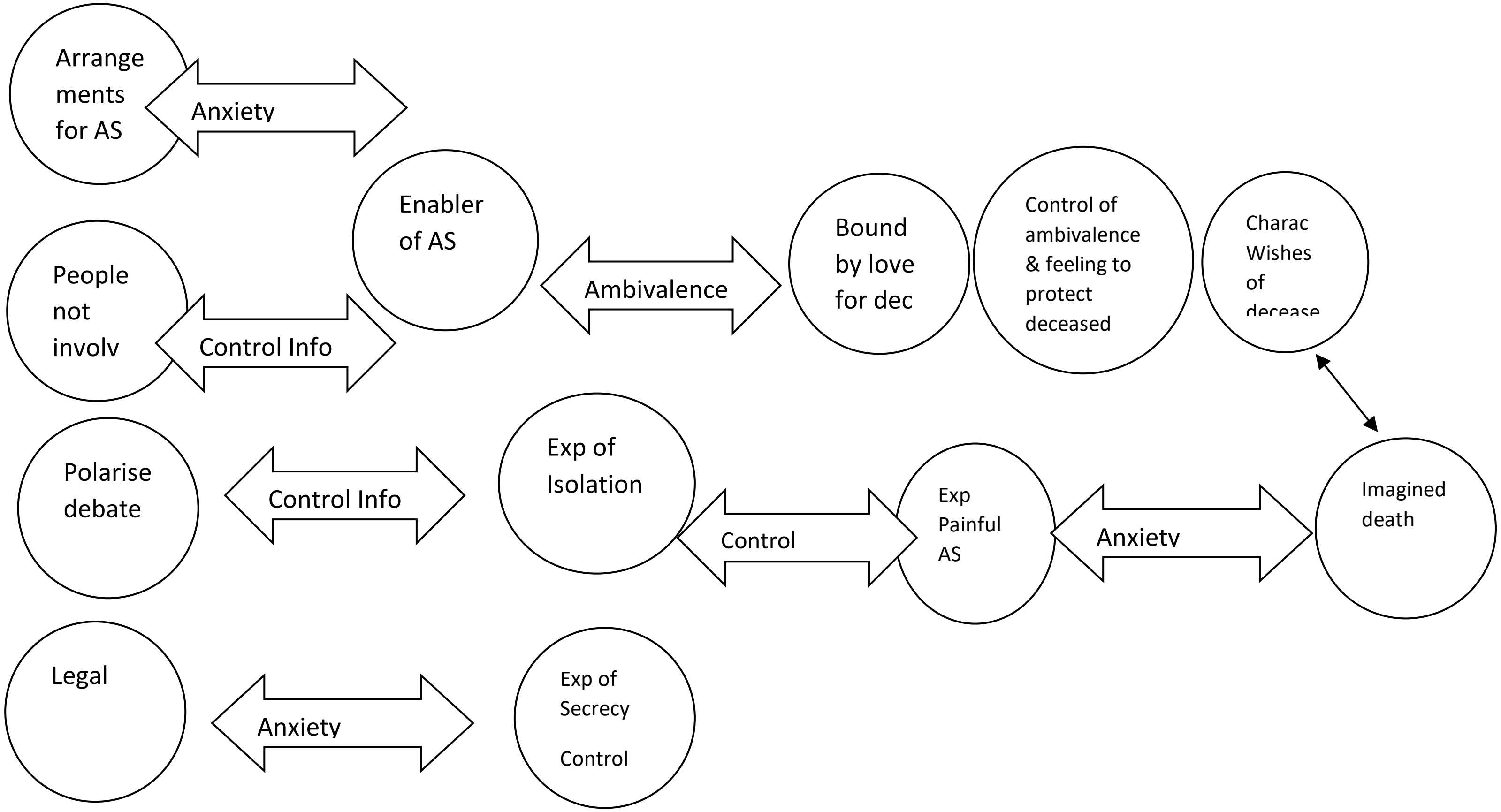
Doubts might lead to guilt about decision or pain caused by events

Any guilt or blame is directed towards the need for a change in the law

Becoming a campaigner links with suppression of doubt or ambivalence

Motivation to participate and likely suppression of some issues within interview

Appendix J Figure b.
processes and relationships between different experiences of bereavement following assisted suicide



ANXIETY – caused by imagined death and need to carry out wishes of person choosing an assisted suicide

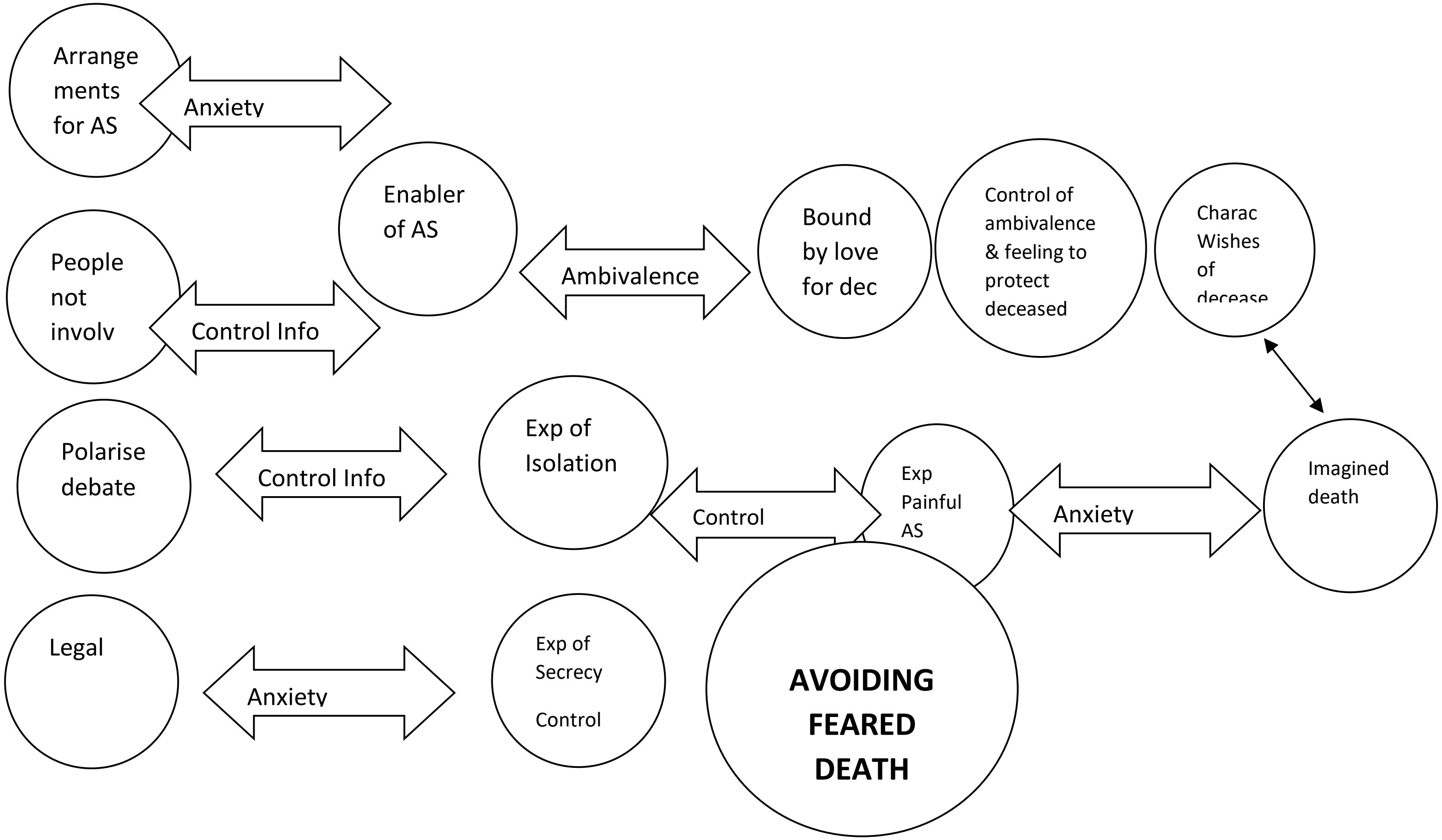
ANXIETY – caused by polarized debate and legal framework

SUPRESSION/CONTROL - need to control feelings and ambivalence due to anxiety about imagined death and pain of AS

SUPRESSION/CONTROL – need to control flow of information to those who were not to know about planning of AS

ISOLATION SOCIAL – caused by secrecy about AS and need to control information to others

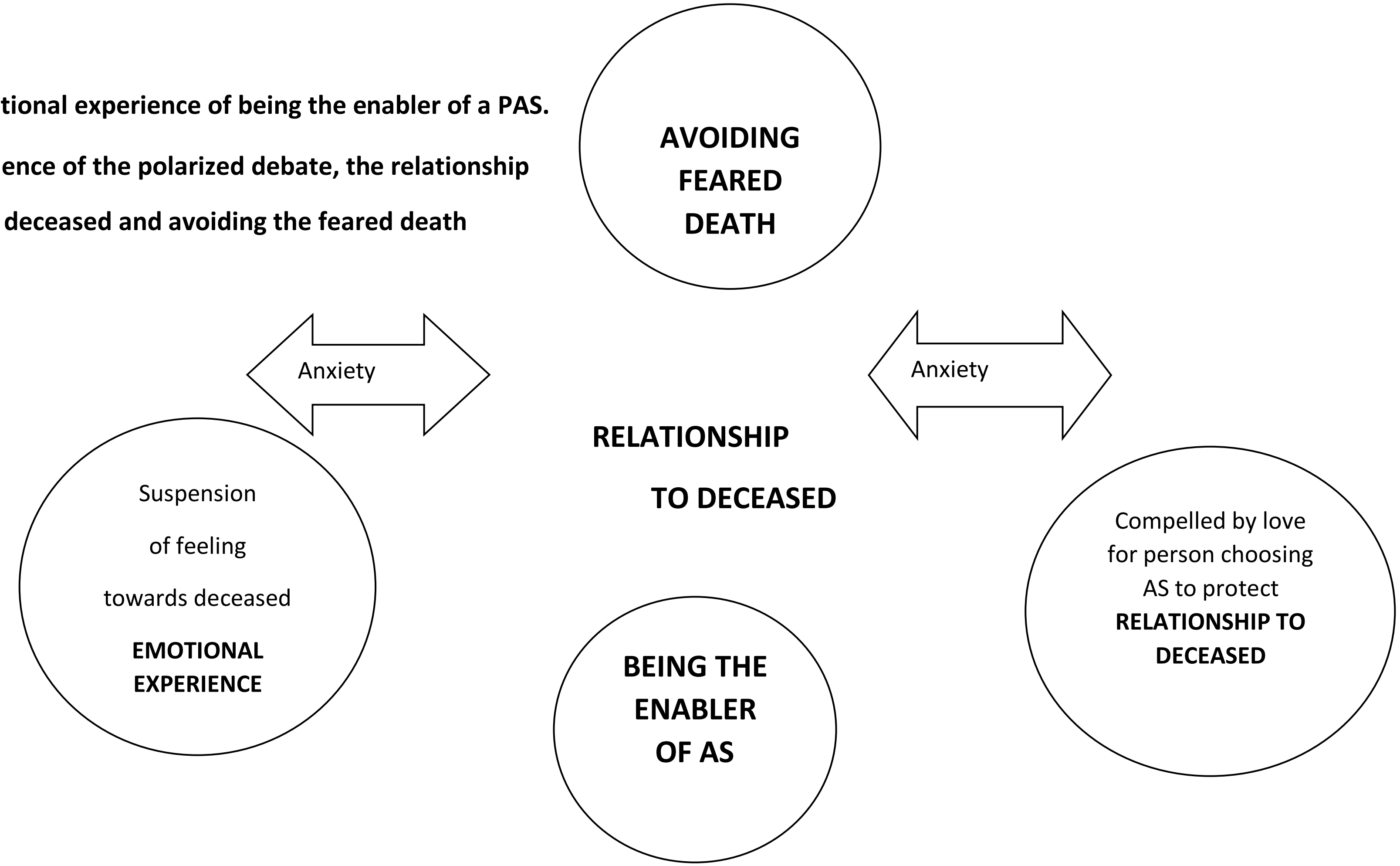
ISOLATION EMOTIONAL – caused by suppression of feelings and lack of emotional opportunities for expression



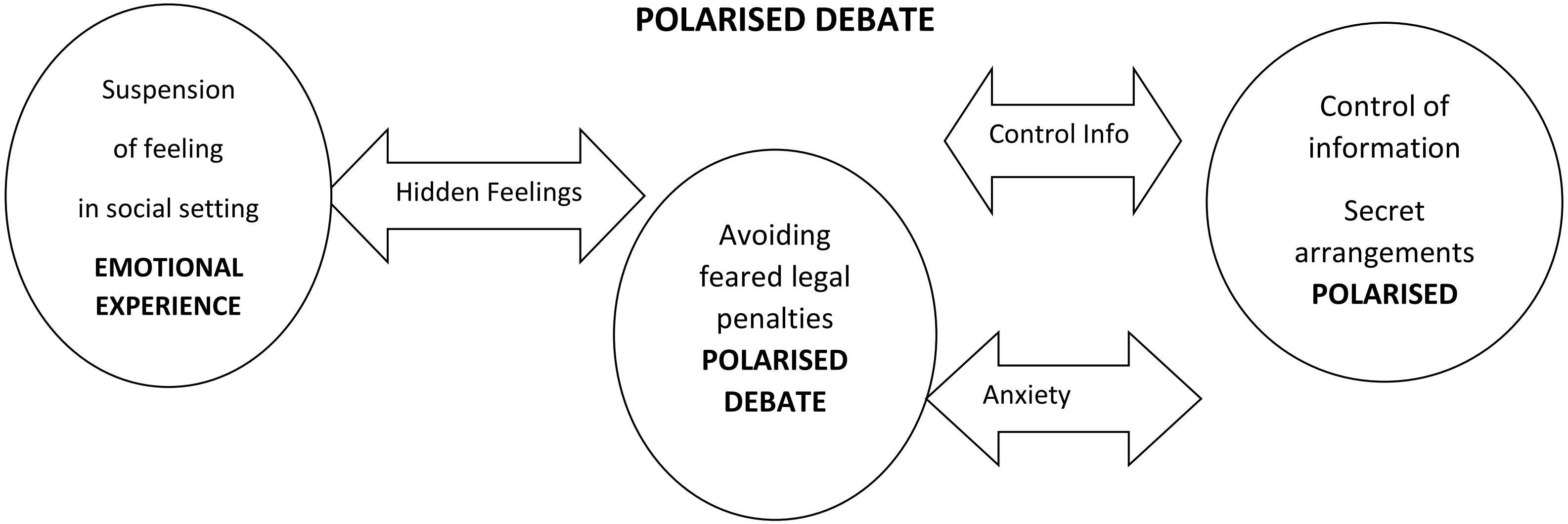
Appendix J c Review back to the experience of enabling and campaigning.

The emotional experience of being the enabler of a PAS.

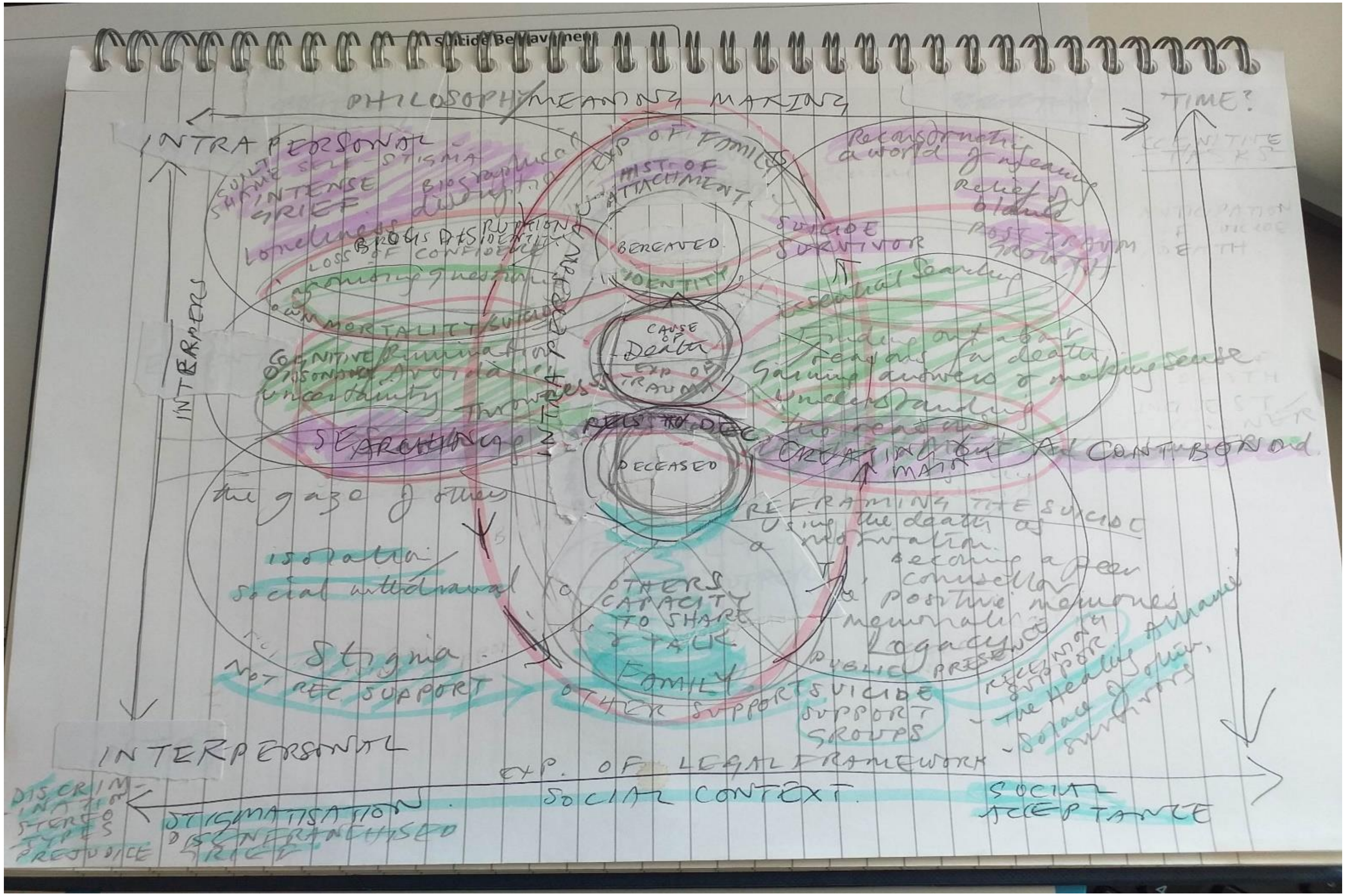
The influence of the polarized debate, the relationship with the deceased and avoiding the feared death



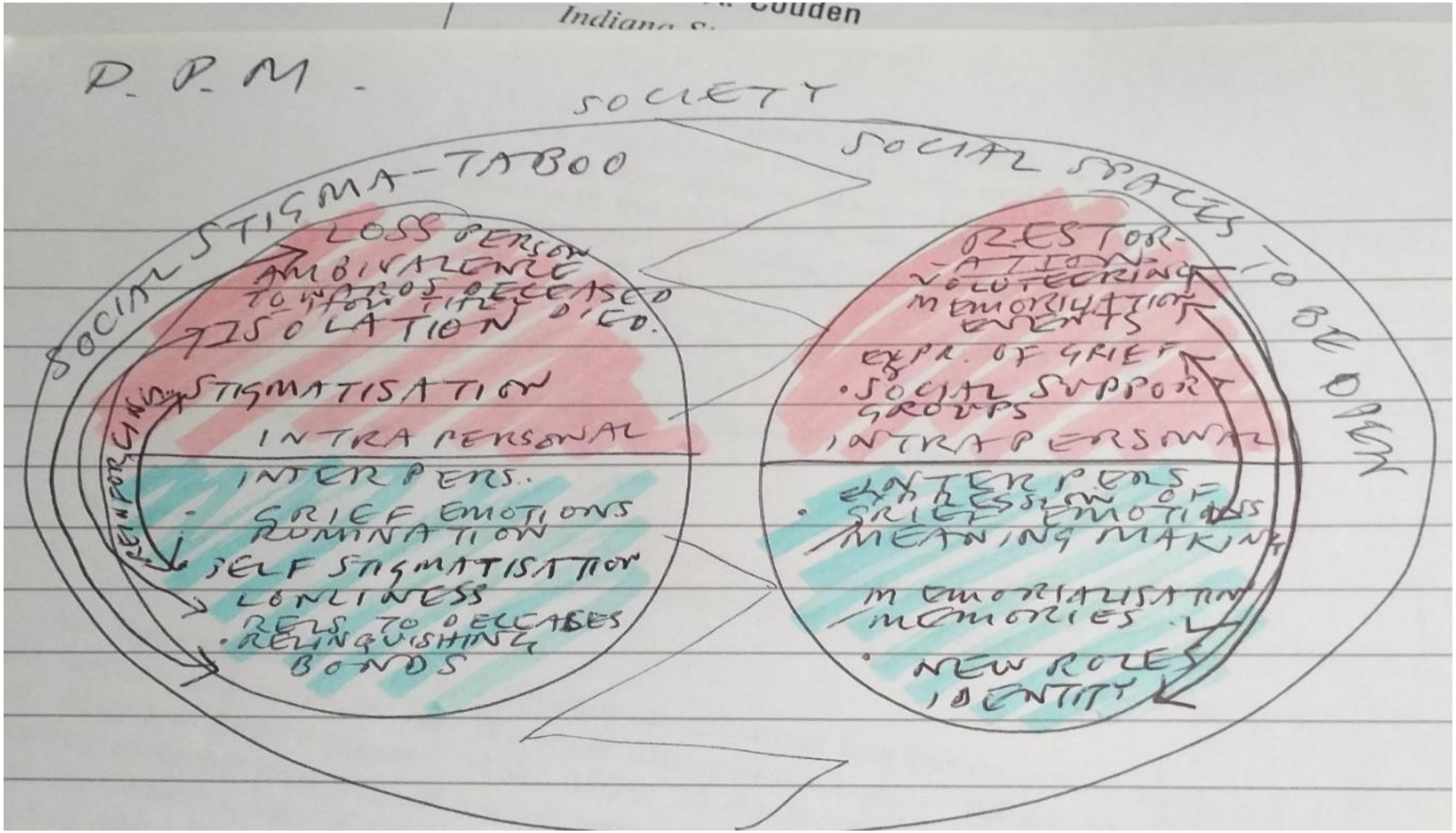
POLARISED DEBATE



Appendix J Figure d Drawing used to develop theoretical model



Appendix J Figure e**.** using the dual process model to consider stigma, before and after the death



Appendix K
Conference Presentation

Designing research - a study on the impact on families of assisted dying

Janette Fish

Supervisors

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We concentrate on the patient but how is this affecting the bereaved?

‘In 2013, Siep Pietersma's family gathered round as he took his own life.

Siep made the decision to end his life after he was diagnosed with dementia.

He had watched his mother lose her mind, and lived in fear of ending the same way.’

http://www.radioaustralia.net.au/international/2015-04-10/euthanasia-in-the-netherlands-one-familys-experience-of-a-loved-ones-assisted-suicide/1435570

Who are these bereaved people living in the UK?

Between 1998-2012, 215 people from the UK travelled to the Dignitas clinic in Switzerland, including 33 people in 2012 (last available data (Dignitas 2014))

Any death can be expected to create on average six bereaved people, and with a suicide there can be a ‘ripple effect’ to other wider family members or friends (Stroebe & Schut, 2001)

There is a growing number of people bereaved in this way

What do we know about them?

No research about those bereaved by assisted suicide in the UK

Limited research on the experience or possible effect on the family members of those who choose to end their lives with assistance in the countries that now have a legal framework to support this process (Gamondi, et al 2015)

This limited research reaches divergent conclusions

Defining our terms?

What do we mean by assisted suicide?

The language used to describe an assisted death

physician assisted suicide (PAS)

or **physician assisted death (PAD)**

usually used to describe an assisted death in Switzerland (Bosshard, et al 2008)

In Holland where a health professional directly administers the means of death, this would usually be described as **euthanasia**

See NHS Website link for description of passive, voluntary, non-voluntary and in-voluntary. See BMA for description of other countries

How can I best answer the questions that need to be addressed?

A qualitative study would allow exploration of this population whose experience has been little recorded and who might be at some risk

It would give insight into particular aspects of the experience of being bereaved by a PAS and how this might differ from other bereavement experience

Semi-structured interviews will collect data from UK residents who have been bereaved by assisted suicide which will have occurred in countries that do enable PAS

In other words I could ………………………………………

Listen to their experience

Designing and planning

Is this research possible?

How can I find these people?

Will they want to participate?

How can I best find out what I think I need to know about?

Who knows about this and can guide me in finding out more about these bereaved?

Has someone close to you travelled to Switzerland* to end their life?

CALL FOR RESEARCH PARTICIPANTS

Would you like to help us to understand how this has affected you?

This research is exploring how a physician assisted death affects the bereaved.

If you would like to participate and find out more information about this research project please contact me via email:

j.fish@lancaster.ac.uk

I look forward to hearing from you

Janette Fish

PhD Student, University of Lancaster

If you know someone who may be interested in participating please pass this invitation on

www.bereavementresearch.wordpress.com