

**What is the experience of assisted dying for  
Dutch healthcare staff working in a hospice  
or chronic disease care centre?**

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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.

## Abstract

*What is the experience of assisted dying for Dutch healthcare staff working in a hospice or chronic disease care centre?*

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**Background:** Assisted dying is a contemporary issue with worldwide interest. Debate has largely focused around individuals seeking the right-to-die. Lacking thus far has been consideration of the experience of clinical staff. This research was conducted at a chronic disease centre and a hospice in the Netherlands where permissive legislation was first enacted.

**Aim:** The aim of this research was to explore and gain a deeper understanding of the assisted dying experience of Dutch healthcare staff to inform and broaden the global debate.

**Methods:** This study provides the first application of a constructivist qualitative inquiry with three professional groups to analyse the care experience of 21 doctors, nurses and therapists practising in the Netherlands. Data from semi-structured interviews were analysed using thematic analysis to identify latent and semantic themes from which new insight was gained.

**Findings:** Requests for an assisted death were received and processed by all staff groups. Large numbers were heard at the hospice where fifty percent of the patients wanted to discuss it. Requests required an assessment of seriousness, an exploration of patient fears and an evaluation of psychological status. Optimum palliative care had to be ensured. Such measures were found to resolve or delay the majority of requests.

Assisted deaths challenged staff and were perceived as not normal. The administration of lethal drugs and post-death case scrutiny were stressful for doctors. After death debriefing and psychological support were valued by staff, but adjustment took some time. Doctors reported a recovery period in which they were unable to respond to further requests rising equity of access issues.

The involvement of nurses and therapists, including activities previously unreported, safeguarded patients. The provision of assisted dying was perceived as significantly increasing workload, but this was not resented. Support for the provision of assisted dying was overwhelming, but this was unqualified in only a third of participants.

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# Chapter One: Introduction and Background

## 1.1 Introduction to Thesis

The focus of this research is to explore the experiences of staff of caring for patients who request and, in some cases, achieve an assisted death in the Netherlands. Assisted dying is a sensitive and controversial topic and is currently permitted in a limited number of places globally. The term assisted dying is defined as:

*“A compendium that can refer to voluntary euthanasia and/or assisted suicide”* (Commission for Assisted Dying 2012, p.37).

This generic term is used in this thesis because there is worldwide variation in the use and meaning of terms related to the deliberate hastening of death (Commission for Assisted Dying, 2012). Other terms used frequently in this thesis are defined on page 21-22.

Throughout the world, public attitudes towards assisted dying fluctuate geographically (Emanuel, Onwuteaka-Philipsen, Unwin and Cohen, 2016), but in Western Europe acceptance levels appear to be becoming more permissive (Cohen, Van Landeghem, Carpentier and Deliens, 2014). Globally there are large volumes of published material related to assisted dying but the practical and psychological implications of the experience for healthcare practitioners,

as reported by the British Medical Association (2016), lacks exploration. This is of concern as, despite a comprehensive defeat for the *Assisted Dying Bill* (House of Lords, 2017) in the United Kingdom in 2016, worldwide the number of jurisdictions, defined as countries, states or federal districts, permitting assisted dying is increasing. The topic, however, remains controversial and divides opinions including within palliative care (Materstvedt, 2013; Chambaere, Cohen, Bernheim, Vander Stichele and Deliens, 2016).

To inform the debate, this study focuses on the experience of Dutch staff who have the longest history of assisted dying in practice. Variation exists in the permitted practices globally, but nonetheless the analysis of Dutch staff experiences provides valuable insights that maybe useful to practitioners, professional bodies, organisations and policy makers.

Chapter One includes the background and context to the study, including an historical perspective and provides a definition of the key terms. It includes a global overview of assisted dying legislation and the development and characteristics of Dutch law. Constructivist inquiry requires the reconstruction of participants' accounts which may be influenced by the researcher's own assumptions, background and discipline specific perspectives. Therefore a reflective account is included in Chapter One positioning the researcher in relation to the topic and research sites. Chapter Two is a literature review exploring what is already known about doctors', nurses' and therapists'

experiences, whilst Chapter Three describes the methodology and methods used in this study, including epistemology, ontological and ethical considerations. Chapter Four contains an account of the research findings. Discussion of these findings and conceptualisation of the emerging themes from the data analysis can be found in Chapter Five which also includes the strengths and limitations of the study. The concluding Chapter Six includes a summary of the main findings, my final reflections and recommendations for practice. This thesis contains sensitive material related to end-of-life care which may cause distress.

## **1.2 Background and Context**

An interest in death and the manner of dying is common in many cultures. Historically, death most frequently occurred in epidemics of infections, but public health measures and medical advancements in wealthy nations (Kellehear, 2007) have aided the survival of patients with previously fatal conditions.

Assisted dying debates often focus on individuals who wish to determine the timing of their own death. In the United Kingdom cases, such as Diane Pretty (British Broadcasting Corporation, 2002) who had motor neurone disease and Tony Nicklinson (Boseley, 2012), with locked-in syndrome, have increased

pressure on policy makers to consider permitting assisted dying. A fellow activist, Debbie Purdy (Williamson, 2014), successfully lobbied for guidance on the prosecution of assisters (Crown Prosecution Service, 2014) after the Court of Appeal (Hirsch, 2009) denied her request for assisted dying to be made legal. Arguably other cases worldwide have had greater impact; such as Brittany Maynard in the United States (Cable News Network, 2014) and Sue Rodriguez in Canada (Stingl, 2010), in that an assisted death is now permitted in California and Canada.

### **1.3 A Reflective Account**

It was shortly after qualifying in 1987 that palliative care was suggested to me as an option, but I dismissed it at the time as unglamorous. After a variety of clinical posts, and a brief flirtation with district nursing, a specialist nurse practitioner (Macmillan) position became vacant. Encouraged to apply I spent nine years in the post before moving to a Senior Lecturer role in Palliative Care in Higher Education which I held until 2017. With a husband, now retired, in medical practice I have also had exposure to, and gained insight, into the professional demands on doctors.

Despite my years of working with dying people, prior to embarking on this study I held no fixed opinions on assisted dying, but had no objection on moral

grounds. For a previous academic module I had reviewed global assisted dying legislation, but I could not envisage how staff managed an assisted death in practice. Nonetheless, interested in the ethical and political debate, I visited Demos, a political think tank, in London to listen to evidence presented to the Commission for Assisted Dying in 2011. The Commission findings led to the *Assisted Dying Bill* (House of Lords, 2017) ultimately defeated in the House of Commons. At the hearing, and in its final report, the Commission cited a paucity of studies related to staff experience which represented a significant knowledge gap.

On a later visit, to a healthcare facility in the Netherlands, assisted dying was discussed by staff informally. Fluid and open conversations, some over lunch, included insights into assisted dying I had not seen published. Although initially shocked at hearing the word 'euthanasia' being used openly by staff, they were candid about the challenges of assisted dying cases in practice. Of prime interest to me was the nursing experience, but the challenges expressed by medical staff also resonated. After deciding the topic may be suitable for my continuing studies the staff were encouraging of my efforts to find out more, suggesting the facility as a possible research site subject to the necessary approvals. As assisted deaths are relatively rare in clinical practice, a local hospice was also suggested as a possible second site. My previous experience of working abroad and my close proximity to an airport in the United Kingdom,

gave me confidence that any problems, or at least any practical issues, could be overcome. The purpose of the study was not to argue for or against the practice of assisted dying, but to gain greater insight into the experience of Dutch staff to add the perspective of staff to the debate where legislation is being considered or implemented.

#### **1.4 An Historical Perspective**

The Netherlands with a population of approximately 16.8 million (World Bank, 2017) has, since the seventeenth century, attracted foreign interest because of its liberal stance on religious and intellectual issues (Griffiths, Bood and Weyers, 1998). Most notably since 1947, in an increasingly secular society, individualisation and democratisation have allowed the open debate of controversial medical topics such as assisted dying and abortion (Griffiths *et al*, 1998).

Beyond the Netherlands however, assisted dying is recognised as a sensitive topic (Warnock and Macdonald, 2009). It is often associated with Nazi Germany where, fuelled by the ideology of eugenics and the creation of a perfect race (Smith, 2008), the physically and psychiatrically ill (Foth, 2012) and the disabled, including children (Atherton, 2013), were involuntarily euthanized at 'euthanasia institutes' often attached to hospitals. In a climate of intense

propaganda doctors and nurses, selected for their discretion and obedience with enhanced pay, worked in pairs killing patients deemed by the Nazi authorities as “*lives not worthy of life*” (Benedict and Kuhla 1999, p.247). This led to the deaths of more than 70,000 ‘incurable’ patients (Manning, 1998), despite euthanasia never being legal in Germany.

After World War II reaction to such activities led to a worldwide restatement of the Ancient Greek Hippocratic Oath (circa 460-377 BC), albeit with adaptations such as removing references to Greek mythology (Smith, 2008). Some writers challenge its relevance in modern, multidisciplinary, and patient-focused healthcare (Walton and Kerridge, 2014), but its central tenet is to ensure that patients are not harmed (Walton and Kerridge, 2014). A reflection on German activities in the Second World War is the “*slippery slope*” (p.53) argument (Jackson, 2012) which suggests that permissive assisted dying law might expose the poor, disabled, elderly, the uninsured, and minority ethnic and racial groups to professional harm (Golden and Zoanni, 2010; Jackson 2012).

Vigilance and careful scrutiny will always be needed but, where statistics have been explored (Battin, van der Heide, Ganzini, van der Wal and Onwuteaka-Philipsen, 2007; Emanuel *et al*, 2016), evidence of the abuse of vulnerable groups is lacking although opinions differ as to whom may be considered

vulnerable. Finlay and George (2011) for example, highlight the potential of depression at the end of life to heighten patients' vulnerability, an issue discussed in Chapter Five (5.3.1.1). Although assisted dying, when permitted, appears to be a preferred option for a relatively small number of patients, case numbers tend to rise over time (Gamondi, Borasio, Limoni, Preston and Payne, 2014). Assisted dying remains therefore, a justifiably sensitive topic.

## **1.5 Assisted Dying in a Global Context**

Worldwide, when considering assisted dying, the term 'jurisdictions' (Commission for Assisted Dying, 2012) is used because, as noted earlier, where legislation exists it may apply to a country, such as the Netherlands, but also to a smaller territories such as Oregon or Washington D.C. in the United States. Where permitted there are two assisted dying options. Euthanasia requires the administration of lethal drugs by a healthcare professional at the patient's request (Emanuel *et al*, 2016). In the second option, physician-assisted suicide, also called physician-assisted dying (Emanuel *et al*, 2016), the patient self-administers, usually orally, lethal medication prescribed by a doctor. In the United States legislation permits only physician-assisted dying whilst in the Low Countries and Canada (Parliament of Canada, 2016) both euthanasia and physician-assisted dying are permitted. Legislation can vary however, in what is expected of staff. In the Netherlands, doctors are required to be present even

if the patient self-ingests lethal medication (TLRAS, 2002). This is not a requirement of legislation in the United States.

In Europe assisted dying is permitted in the Netherlands by the *Termination of Life on Request and Assisted Suicide Act* (TLRAS, 2002), with similar legislation in Belgium (Kidd, 2002<sup>1</sup>) and Luxembourg (Ministry of Health, 2009). In Switzerland no specific law exists, but under Article 115 of the Penal Code assisting a suicide is only a crime if the motive is selfish (Hurst and Mauron, 2003). Such deaths are usually facilitated by a volunteer from a right-to-die organisation (Bosshard, Ulrich, Ziegler and Bär, 2008) and are rarely prosecuted (Hurst and Mauron, 2003). In 2011 the Swiss Federal Council (Federal Council, 2011) decided against altering the existing Swiss law focusing on the right to self-determination of individuals, but also the strengthening of palliative care.

In the Americas assisted dying is permitted in the United States in Oregon (Oregon Health Authority, 2017), Washington (Washington State Department of Health, 2017), Vermont (Vermont Department of Health, 2017), California (California Department of Public Health, 2017), Colorado (Colorado

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<sup>1</sup> An English translation of the Belgian Act of 2002

Department of Public Health and the Environment, 2017) and Washington D.C. (District of Columbia, 2017). Constitutional review in Columbia, South America, altered the Penal Code in 1997 (Michlowski, 2009), but a Bill codifying assisted dying was overturned in 2007 (Michlowski, 2009). The creation of procedural guidelines for doctors however, led to an assisted death in July 2015 (Dyer, White and Rada, 2015). In North America the Canadian province of Quebec ratified legislation in 2013 (Assemblée Nationale Québec, 2017), with federal legislation in Canada being passed in June 2016 (Parliament of Canada, 2016). The criteria for an assisted death where it is permitted globally, including the reporting and monitoring procedures, are summarised in Appendix 1.

## **1.6 Assisted Dying and Palliative Care**

Globally, there is an uneasy relationship between assisted dying and palliative care. The deliberate hastening of death is not endorsed in the World Health Organisation's goals of palliative care (World Health Organisation, 2017).

Furthermore, where assisted dying is permitted, there are conflicting views of whether or not an effective synergy is desirable or possible (Vanden Berghe, Mullie, Desmet and Huysmans, 2013; Randell, 2013). The majority of palliative care associations are not in favour of its inclusion (Materstvedt and Bosshard, 2015) with the exception of those in Flanders (Vanden Berghe *et al*, 2013).

Recent positional reviews by the European Association for Palliative Care (Radbruch *et al*, 2016) and the International Association for Hospice and Palliative Care (De Lima *et al*, 2017) have done little to resolve this controversy. Advocates of integrating assisted dying into palliative care have suggested that reviewing its practical implications may be helpful in resolving this issue (Chambaere *et al*, 2016). By exploring the experience of staff this study is providing useful information which can be added to this debate.

## **1.7 Defining Key Terms**

In the English language the word 'experience' can be used as a noun or a verb; for the purposes of this study 'experience' is defined as:

*"The fact or state of having been affected by, or gained knowledge through direct observation or participation."* (Merriam-Webster, 2015)

This research study focuses on staff experiences in the Netherlands where euthanasia is, by definition, voluntary in nature and only permitted at the request of a patient. Euthanasia is defined as the:

*"Termination of life by a doctor at the request of a patient"* (Royal Dutch Medical Association (2012, para.4).

This is distinct from involuntary euthanasia when a life is ended without request defined as:

*“Intentionally administering medications to cause the patient’s death without the patient’s request and full, informed consent” (Manning 1998, p. 3).*

The following terms are also defined relative to their use in the Netherlands:

- Physician-assisted suicide: *“A physician supplies the lethal drug but the patient administers it” (Government of the Netherlands 2017a, para.1).*
- Palliative sedation therapy: *“The use of specific sedative medication to relieve intolerable suffering from refractory symptoms by a reduction in patient consciousness, using drugs carefully titrated to the cessation of symptoms” (de Graeff and Dean 2007, Abstract)*
- Doctrine of double effect: *“The potential for non-intentional death caused by the administration of legal medication or treatment with the primary intention of relieving suffering” (adapted from Griffiths et al 1998, p.19).*

Global variation exists in the healthcare disciplines considered to provide ‘therapy’. In this study the term therapist includes social workers, dieticians, physiotherapists, speech and language therapists, psychologists, chaplains, creative therapists and activities organisers. A therapist in this study is defined as:

*“Someone whose job it is to treat a particular type of mental or physical illness or disability usually with a particular type of therapy.”*

(Cambridge Dictionary, 2017)

When defining key terms it is necessary to acknowledge that, for some patients, ‘significant people’ in their life may not be members of their immediate or extended family. As however, ‘family’ or ‘family members’ were the terms most commonly used by Dutch staff in this study, the term ‘family’ is used for lay people who care for, or surround the patient, physically and emotionally.

## **1.8 The Dutch Experience of Developing Legislation**

The Dutch assisted dying debate has taken place since the 1950s (Weyers, 2012) when the term ‘euthanasia’ was synonymous with several end-of-life care practices including the ending of life with or without request, withholding of food and fluids, and hastening death due to increased analgesic doses (Weyers, 2012). In the 1970s, however, it became a public issue with several well-known legal cases, illustrated in Appendix 2, leading to the formalisation in law of existing life-ending practices.

Notable Dutch legal cases involving doctors include the *Postma* case (1971). Dr T. Postma was prosecuted for killing her mother, who had been disabled by a stroke, at her request, by injecting her with morphine (ten Have and Welie, 2005). Found guilty in 1973, Dr Postma's sentence was lenient with a jail term of only one week, but the trial raised the issue of when, and under what conditions, drugs could be given to hasten death (Weyers, 2012). Advocates of assisted dying also formed the Dutch Association for Voluntary Euthanasia in 1973 which is still operational (NVVE, 2017). This association provides advice for Dutch citizens on advance care planning, assisted deaths and, in 2013, founded the *Levensindekliniek* or End of Life Clinic (2017) which is discussed later in this chapter (1.10).

The *Alkmaar* case (Weyers, 2012), sometimes named after the defendant doctor Dr Schoonheim (ten Have and Welie 2005), took place in the municipality of *Alkmaar* in the province of North Holland in 1982. Self-reporting his actions to the police Dr Schoonheim killed, by lethal injection, a 95-year old bedridden patient after her written and repeated requests to die (Weyers, 2012). Although initially acquitted, the Court of Appeals later delivered a guilty verdict (Griffiths *et al*, 1998) on the grounds that euthanasia was not legally permitted. This was upheld by the Dutch Supreme Court although it used its discretion not to impose any punishment (Griffiths *et al*, 1998).

The *Alkmaar* case recognised a potential conflict of interest for doctors unable to end life legally, but nonetheless expected to relieve suffering (Griffiths *et al*, 1998). This led to the recognition of ‘justifiable euthanasia’ and the defence of “*necessity*” (Keown, 2012, p.118), or *overmacht* in Dutch (Pans, 2012), by the Royal Dutch Medical Association in 1984. Other cases of euthanasia such as the *Pols* (Griffiths *et al*, 1998) and *Admiraal* cases (Weyers, 2012), resulted in doctors being found guilty and acquitted respectively.

Such cases heightened awareness of the end-of-life care dilemmas for doctors, but also the potential for abuse. As a consequence reporting procedures for assisted dying cases were devised by the Ministry of Justice in 1990 (Griffiths *et al*, 1998). Research into the incidence of assisted deaths was conducted by the *Remmelink Commission*, named after its chairperson (Weyers, 2012), to monitor medical end-of-life decision-making. The Commission first reported in 1991 and suggested that 1.7 % of Dutch deaths were attributable to euthanasia with a further 0.2% to physician-assisted dying.

## **1.9 Current Dutch Legislation**

Assisted dying practices were formally recognised by the *Termination of Life on Request and Assisted Suicide Act* (TLRAS, 2002). This law also applies in the Dutch Caribbean colonies of Bonaire, St Eustatius and Saba, often called the

BSE Islands, but cases here are rare. To be lawful six *'due care'* criteria need to be fulfilled (Appendix 3). These include suffering which is *"unbearable"* (TLRAS 2002, Article 2b) which can be related to physical or psychiatric illness (Royal Dutch Medical Association, 2011). Of the required criteria this is the most contentious with no accepted definition (Dees, Vernooij-Dassen, Dekkers and van Weel, 2010). Research has also highlighted the differing views of what constitutes suffering between patients and doctors (Pasma, Rurup, Willems and Onwuteaka-Philipsen, 2009). Other criteria include a consistent and enduring request, and the applicant being mentally competent at the time of the request.

All potential assisted dying patients must be seen at least once by an independent *'consulting physician'* (Royal Dutch Medical Association, 2011) who assesses the patient to ensure legal requirements are met (Jansen-van der Weide, Onwuteaka-Philipsen, van der Heide and van der Wal, 2009). After concerns about the independence of consulting doctors (Kimsma, 2012) the Support and Consultation Euthanasia in the Netherlands service, often called colloquially after its acronym SCEN, or SCEA after its name in Dutch [*Steun en Consultatie bij Enthanasie in Nederland*] (Kimsma, 2012), now provides such doctors. This service has been largely well-evaluated by doctors (Van Wesemael *et al*, 2010), patients and relatives (Jansen-van der Weide *et al*, 2009). Dutch Support and Consultation doctors, who need five years of medical

experience, receive three days of training spread over eight weeks, and mandatory updates including palliative care (Kimsma, 2012). If however, the patient's mental capacity is in doubt, a psychiatrist must also be consulted.

The 'attending', or regular doctor (Griffiths *et al*, 1998), of a Dutch patient, is provided with guidelines for patients with an advanced directive, patients who are semi-conscious and those with dementia (Review Committees, 2016a).

Guidance is also given in the form of case reviews in the annual Review Committee Reports (Review Committees, 2016b). All Dutch healthcare professionals have a right to conscientious objection, called an 'objection in principle' (Royal Dutch Medical Association, 2011), and can decline involvement in assisted dying cases.

### **1.10 Notification, Reporting and Scrutiny Procedures**

In contrast to the other Low Countries (Lewis, Gerson and Gamondi, 2017) and the United States (Dunn, Reagan, Tolle and Foreman, 2008) Dutch assisted deaths are not classified as 'natural'. Consequently the attending doctor, usually the patient's hospital or family doctor, is unable to complete a death certificate (Griffiths, Weyers and Adams, 2008). A local municipal pathologist (Griffiths *et al*, 2008), colloquially called a 'Forensic Doctor' by staff in this study, is sometimes translated to coroner (Kimsma and van Leeuwan, 2012).

The Dutch role however, differs from the role of a coroner in the United Kingdom. A coroner in the United Kingdom does not have to be a medical practitioner and they do not generally view a body directly after death. A Dutch municipal pathologist is a medical practitioner who can examine the body and clinical records, and who may talk to the attending doctors before filing a report with the judicial Public Prosecutor's Office (Government of the Netherlands, 2017b). A similar role, the medical examiner, has been proposed in the United Kingdom by the Department of Health (2016) to strengthen death certification procedures following the Francis Report and the Shipman Inquiry. In the Netherlands if 'due care' criteria appear to have been followed the Prosecutor's Office will give permission for cremation or burial (Keown, 2002).

All Dutch assisted dying cases are notifiable to one of five Regional Euthanasia Review Committees (Review Committees, 2017) established in 1998. These committees review all reported cases producing an annual report which includes statistics and guidance for clinical practice (Review Committees, 2017). Such committees consist of a lawyer, an ethicist and a doctor, and are seen as necessary to decriminalise medical actions which had previously led to contested legal cases (Kimsma and Leeuwen, 2012). In a complex area of care multidisciplinary review is seen as desirable to promote case reporting (Griffiths, 2012).

Since 1990 and thus predating the current legislation, national surveys of medical end-of-life-decisions have been conducted at approximately five yearly intervals. These surveys, which promise anonymity and immunity from prosecution, help to quantify the incidence of assisted deaths, including those which are not formally reported. The non-reporting rate of assisted deaths has fallen from an estimated 82% in 1990 to 20% in 2005 (Onwuteaka-Philipsen, 2012). Doctors give a variety of reasons for non-reporting. The commonest reason relates to the 'doctrine of double effect' (Huxtable, 2004) and the use of opioids outside of recommended guidelines. Overall the incidence of Dutch assisted deaths has risen over time. In 2010 assisted deaths accounted for 2.8% of all deaths. The most recent publically available statistics, relating to 2016 (Royal Dutch Medical Association, 2017) indicate that assisted deaths now account for 4.14% of all Dutch deaths.

Article Nine of the Euthanasia Law (TLRAS, 2002) allows Review Committees six weeks to report their case conclusions to doctors with a further six weeks permitted if required (TLRAS, 2002). Keeping to this standard has however, proved difficult with the Annual Report of 2013 (Review Committees, 2016b) acknowledging an average waiting time of 127 days. A 'lighter touch' approach for non-complex cases has reduced waiting times with statistics from 2015 (Review Committees, 2016b), the latest available, reporting a 39 day average wait for case closure. Decisions in complex cases may however, be postponed to allow questioning of the doctor in person (Review Committees, 2016a).

Committees judge the doctor's care as being either 'careful' or not (Griffiths *et al*, 2008) in accordance with the due care criteria. Annual reports since 2002 reveal that care has been deemed unsatisfactory in only a small number of cases (Review Committees, 2016b) with no criminal prosecutions (Kimsma and van Leeuwen, 2012). Committees can also, however, apply pressure at an institutional level if poor care is identified, via the prosecutorial authorities or the Medical Inspectorate (Griffiths *et al*, 2008).

Subject to the same reporting and scrutiny procedures, a controversial development (Sheldon, 2012) is the End of Life Clinic, *Levensindekliniek* in Dutch (End of Life Clinic, 2017). This clinic offers a service to patients who meet the legal criteria for an assisted death, but whose regular doctors are unwilling to participate or have rejected their request (Snijdewind, Willems, Deliens, Onwuteaka-Philipsen and Chambaere, 2015). Patients are assessed by a mobile doctor and nurse team (Sheldon, 2012) at their place of residence. If deemed to have a valid request the patient will undergo further assessments, as a minimum with a second doctor and a lawyer.

Approximately half of all requests are refused (Snijdewind *et al*, 2015), but nevertheless, the clinic performed 8.1% of assisted deaths in the Netherlands between 2015 and 2016 (Royal Dutch Medical Association, 2017). The profile of

the clinic's patients, in its first year of operation (Snijdewind *et al*, 2015), is slightly older than the average age for a Dutch assisted death with more patients over 80 years. Proportionally, patients were also more likely to have dementia or a psychiatric illness (Annual Report 2015, Review Committees, 2016b). This is perhaps not surprising as they may already have been declined an assisted death by their usual doctor. As most of the clinic's cases are 'complex' in nature, all cases are subject to individual scrutiny. The clinic's statistics are reported separately in the Review Committee Annual Reports (Review Committees, 2016b).

### **1.11 Summary of Chapter**

Often with a media focus on individual cases, public and political pressure has slowly increased the number of jurisdictions that permit assisted dying globally. At the start of this study it was permitted in the Low Countries of Europe and in Columbia. In the United States a physician-assisted death is permissible in the States of Oregon, Washington, Vermont, California and Colorado, and in the Federal District of Washington D.C. In Switzerland no specific law exists, but assisting a suicide is only a crime if the assister's motive is selfish. However, with a conflicted relationship a minority of palliative care professional associations support the inclusion of assisted dying in practice.

Of all the jurisdictions globally permitting assisted dying, the Netherlands has the longest history with case law predating the current legislation enacted in 2002. Often linked to Nazi practices in the Second World War, assisted dying retains its status as a sensitive topic. The political climate and the legal cases involving doctors that led to the legalisation of assisted dying in the Netherlands have been summarised. Dutch law, the *Termination of Life and Assisted Suicide Request Act of 2002*, codified existing practices and permits euthanasia, and physician-assisted suicide if six specific criteria are met. Specific notification and reporting procedures are applied to such deaths which are considered 'unnatural'. Multidisciplinary Review Committees scrutinise cases although, due to the workload, this often takes longer than the time-frame specified in the 2002 Act. No prosecutions have occurred to date since the 2002 Act, but disciplinary proceedings have taken place with sanctions levied.

# **Chapter Two: Literature Review**

## **2.1 Introduction**

In Chapter One the nature of assisted dying legislation globally, the historical development of assisted dying in the Netherlands and the requirements of the Dutch Euthanasia Law (TLRAS, 2002) were reviewed. Although assisted dying is a common topic for debate, the exploration of the experience of staff is often neglected in reviews (Rietjens, van der Maas, Onwuteaka-Philipsen, van Delden and van der Heide, 2009). A literature review, which can take many forms (Cooper, 1998), is required to synthesise the current state of knowledge and to highlight important issues that are outstanding.

## **2.2 Literature Review Method**

A systematic 12 step method, advocated by Kable, Pich and Maslin-Prothero (2012) (Table 1), has been undertaken to search for relevant literature to answer the review question in 2.3. Critical appraisal has been followed by the identification of themes, and a narrative review of themes for the staff groups of doctors, nurses and therapists.

**Table 1: Kable et al (2012) 12 Step Literature Review**

<b>Kable et al (2012) Search Strategy</b>	<b>Evidence in Thesis</b>
1. Provide a purpose statement	Focus of the Review
2. Document the databases or search engines used	All sections in 2.4 'Search Strategy'
3. Specify the limits applied e.g. dates, language	
4. Inclusion and exclusion criteria	
5. List the search terms used	
6. Document the search process	
7. Assess the retrieved articles for relevance	
8. Document a summary table of included articles	Summary Table: Appendix 4
9. Provide a statement specifying the number of retrieved articles at the end of the process	Overview of Included Papers
10. Conduct a quality appraisal	Appraisal of Papers
11. Critical review of the literature	Narrative Review
12. Check reference list for accuracy	Conducted, but not reported on

## **2.3 Focus of the Review**

The focus of this review was to provide an answer to the following question:

*'What is the experience of doctors, nurses and therapists caring for patients who request and, in some cases, achieve an assisted death'?*

Searching and reviewing the literature has been an iterative process since March 2013 up to August 2017. This has been essential to keep abreast of new and potentially, relevant research.

## **2.4 Search Strategy**

### **2.4.1 Databases and Search Engines**

Databases were chosen for their relevance to healthcare practice in medicine, nursing and therapies allied to health. A broad approach (Dundar and Fleeman, 2014) has been taken to obtain papers on the assisted dying experience of doctors, nurses and therapists. The databases accessed were the Cumulative Index to Nursing and Allied Health Literature [CINAHL], Medical Literature Analysis and Retrieval System Online [MEDLINE], Allied and Complementary Medicine [AMED], PsycINFO and Excerpta Medica Database [EMBASE]. Citation tracking of key articles was conducted via Web of Science. The WorldCat library catalogue and ETHos were used to obtain details of relevant books and theses.

### **2.4.2 Limiters, Inclusion and Exclusion Criteria**

Limiters were applied to the search strategy (Kable *et al*, 2012) to ensure that retrieved material was accessible in terms of language and relevant to the focus of the review. These are shown in Table 2 overleaf.

**Table 2: Inclusion and Exclusion Criteria**

Inclusion Criteria	Exclusion Criteria
Published in English	
Empirical research	Opinion pieces Theoretical papers Case studies
Euthanasia and/or physician-assisted suicide in jurisdictions where assisted dying is permitted	Papers related to hastening of death by other means e.g. withdrawal of fluids or foods
Experiences of doctors, nurses or therapists	Papers related primarily to staff opinions or attitudes
Data collection from the date of permissive legislation or, in the Netherlands, from 1999.	

Empirical human studies were sought in the English language. The review is also focused on assisted dying as opposed to other means of hastening death such as the withdrawal of treatment, food or fluids. Initially papers related to assisted dying and the experience of staff in the Netherlands were sought. A paucity of papers however, particularly for Dutch nurses and therapists, led to an extension of this strategy to include other jurisdictions where permissive legislation existed at the time of the literature review; namely Belgium, Luxembourg, and Oregon and Washington State in the United States. This led to the discovery of relevant empirical papers from Belgium and Oregon relating to doctors, and also nurses and therapists.

Specific attention was given to time-limiters with papers only included if assisted dying was legally permitted when data was collected. This time-limiter

however, was expanded for Dutch papers as relevant papers were not numerous. Several Dutch papers also straddled a transitional zone (Norwood, 2007; van Bruchem-van de Scheur *et al*, 2008a) between pre-existing practice and legislation (TLRAS, 2002). This may reflect high interest levels at a time of change. Therefore, papers relating to Dutch staff were included if data collection took place from 1999 pre-dating the Euthanasia Act (TLRAS, 2002) by three years. This flexible approach, advocated by Cooper (1998), permitted the inclusion of a greater numbers of potentially relevant studies to aid the validity of the review.

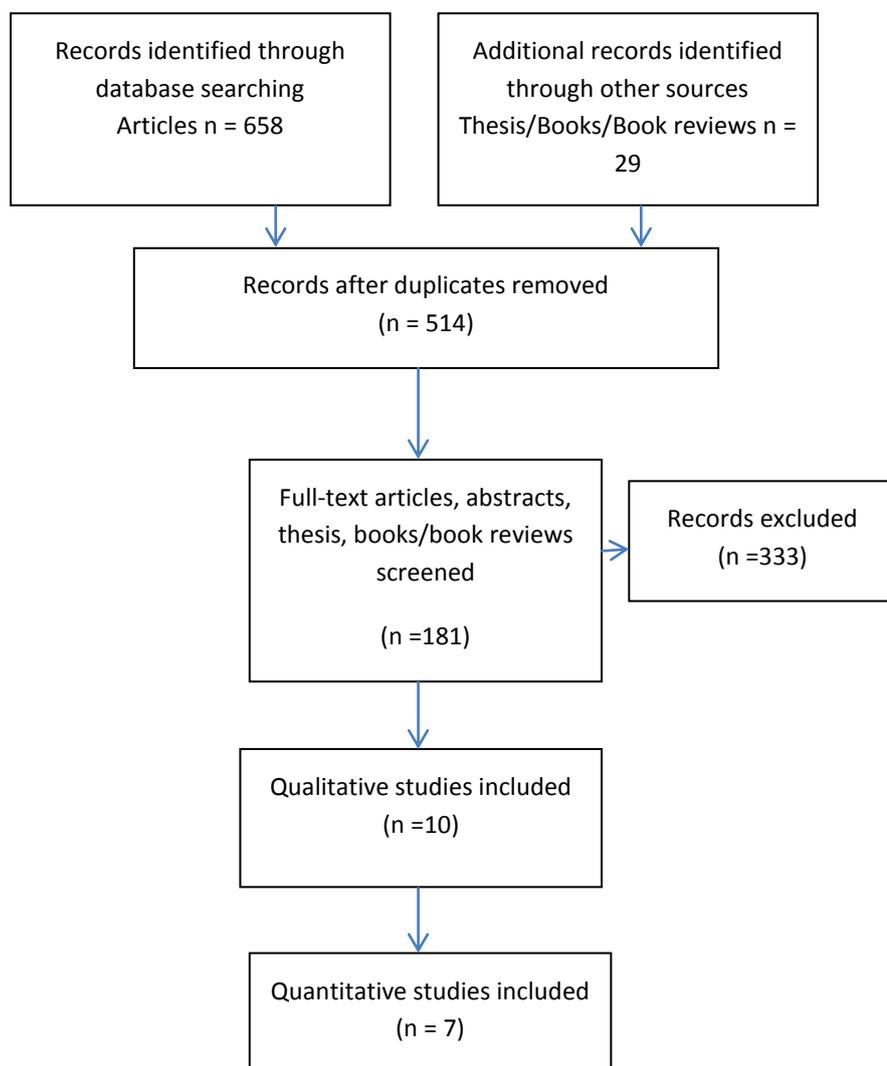
Of the included papers some contained staff experiences of assisted dying alongside those of patients (Borgsteede *et al*, 2007) and relatives (Snijdewind, van Tol, Onwuteaka-Philipsen and Willems, 2014), or included staff groups in geographical areas where assisted dying is not permitted (Voorhees, Rietjens, van der Heide and Drickamer, 2014). If the experiences of staff relevant to the review question could be isolated from the other groups, they were retained (Borgsteede *et al*, 2007; Snijdewind *et al*, 2014; Voorhees *et al*, 2014). This was preferable to exclusion, as relevant empirical studies were comparatively rare. Where multiple publications arose from the same data set, only the most appropriate paper was appraised, but associated papers are noted in the Summary Table (Appendix 4) discussed later in 2.6.

### **2.4.3 Search Terms**

To ensure that relevant material was identified search terms were reviewed by a subject-specific librarian prior to searching databases. Search terms, as shown in Appendix 5, were truncated to include plurals and associated terms, in a structured approach to searching for papers (Kable *et al*, 2012).

### **2.4.4 Documenting the Search Process**

A PRISMA flowchart (Alessandro *et al*, 2009) illustrating the search process used in the literature review is shown in Figure 1 overleaf.



**Figure 1: PRISMA Flowchart of Appraised Papers**

## 2.5 Overview of Included Papers

Fifteen studies met the inclusion criteria for this review study with an additional two papers (Francke, Albers, Bilsen, de Veer and Onwuteaka-Philipsen, 2016; Norton and Miller, 2012) captured through citation tracking at a later date. Of these papers eight are from the Netherlands, six are from the United States and three are from Belgium. One paper (Voorhees *et al*, 2014) includes staff from the Netherlands and United States. Appraised studies from the United States all focus on Oregon. One Oregonian paper was discounted as although it included some quotes from doctors there was a lack of clarity surroundings its purpose (Chin, Hedberg, Higginson, Fleming, 1999). Papers from Belgium all originated from Flanders, the Dutch-speaking northern part of the country. No relevant papers from Luxembourg were found. The country of origin of the appraised papers and the professional groups of staff who participated are shown in Table 3 overleaf. Included studies usually relate to a single professional group, but there are occasional exceptions.

**Table 3: Country of Origin and Professional Group of Appraised Papers**

	<b>Doctors</b>	<b>Nurses</b>	<b>Therapists</b>
N E T H E R L A N D S	Van Marwijk <i>et al</i> (2007) Borsteede <i>et al</i> (2007) Norwood (2007) Georges <i>et al</i> (2008) Voorhees <i>et al</i> (2014) Snijdewind <i>et al</i> (2014)	van Bruchem-van de Scheur <i>et al</i> (2008) Francke <i>et al</i> (2016)	
U S A	Ganzini <i>et al</i> (2000) Dobscha <i>et al</i> (2004) Voorhees <i>et al</i> (2014)		Ganzini <i>et al</i> (2002) Carlson <i>et al</i> (2005) Norton and Miller (2012)
		Ganzini <i>et al</i> (2002)	
B E L G I U M		Inghelbrecht <i>et al</i> (2010) Dierckx de Casterlé <i>et al</i> (2010) Bilsen <i>et al</i> (2014) [proxy reporting]	

## 2.6 Appraisal of the Papers

A structured approach to appraisal is recommended to strengthen the quality of literature reviews (Dixon-Wood, Agarwal, Young, Jones and Sutton, 2004).

Therefore, critical appraisal checklists were used to standardise the appraisal of included papers. Qualitative papers were appraised using the National Institute of Clinical Excellence (2012a) Checklist for Qualitative Studies designed to accommodate a variety of approaches. Overall assessment of each paper was aided by the scoring system shown overleaf in Table 4.

**Table 4: Grading System for Qualitative Papers (National Institute of Clinical Excellence, 2012a)**

++	All or most of the checklist have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter
+	Some of the checklist criteria have not been fulfilled, where they have not been fulfilled or not adequately described the conclusions are unlike to alter.
-	Few checklist criteria have been fulfilled

The Summary Table in Appendix 4 includes the design of the study, sample size and sites, key findings, appraisal scores and associated papers. A narrative review in Section 2.8 will discuss the themes arising from this appraisal including by professional group. All the included quantitative studies were surveys. These were appraised using a checklist available from the British Medical Journal (2017). This checklist, used for appraisal in clinical guidelines from the National Institute of Clinical Excellence (National Institute of Clinical Excellence, 2012b), was chosen as a 'best fit' option for the included quantitative studies. Synthesising the results of quantitative and qualitative papers is acknowledged as problematical (Dixon-Wood *et al*, 2004), but is undertaken here to ensure the broadest view of the topic under study.

## **2.7 Critical Review of the Literature**

Themes arising in the literature, in each professional group, are identified and discussed in 2.8, and a critical review (Bryman, 2016) of the appraised papers is included below. In the critical review issues related to the use of terminology in appraised papers, the rigor of the data analysis methods used, sampling, and the reuse of questionnaires are considered.

### **2.7.1 Terminology Use**

Of the appraised papers, only 37% supply definitions of key terminology such as the delivery method of the lethal drugs which relate to actions by a patient such as swallowing (physician-assisted suicide), or to an injection given by a doctor (euthanasia). Clear definitions of these terms are necessary to clarify what is seen as lawful in the jurisdiction of the inquiry. Moreover, terms are sometimes used generically such as 'physician-assisted dying' (Voorhees *et al*, 2014) for both 'euthanasia' and 'physician-assisted suicide'. This complicates the comparison of papers because legislation, and the actions of the staff required, varies globally (Emanuel *et al*, 2016). As noted earlier physician-assisted dying in the United States, for example, does not require a doctor's presence, but the attendance of a doctor in the Netherlands is necessary for any form of assisted death (Royal Dutch Medical Association and Royal Dutch

Pharmacist Association, 2012). Therefore, terminology needs to be clearly defined and site specific, as it may result in differing experiences for staff.

Clarity of intention is also important in end-of-life care. In Ingelbrecht, Bilsen Mortier and Deliens (2010), the delivery of opioids by nurses is labelled as 'physician-assisted suicide', but, as acknowledged by the authors (p. 908), the intentions of such actions are not explored. Such actions may relate to appropriate symptom management, with opioids being administered to relieve pain, rather than delivering an assisted death (National Institute for Care Excellence, 2016). This paper however, has not been excluded as the numbers of relevant papers is limited. It also illustrates some of the difficulties and challenges of conducting assisted dying research.

### **2.7.2 Sampling Issues**

Purposive sampling (Gray, 2014) occurred in the majority of the appraised qualitative papers, including convenience (Borgsteede *et al*, 2007) and snowball sampling (Snijdewind *et al*, 2014), the latter being appropriate for sensitive topics (Gray, 2014). Purposive sampling however, is prone to bias (Gray, 2014). Convenience sampling, for example, may inadvertently recruit staff with similar views leading to sample bias (Gray, 2014). Notably, assisted

dying research often lacks participants who have an objection, on moral or other grounds. This issue is acknowledged in two of the appraised qualitative papers (Dobscha, Heintz, Press and Ganzini, 2004; Dierckx de Casterlé, Denier, De Bal and Gastmans, 2010) discussed below. Some studies did, however, purposefully seek staff with differing views such as Voorhees *et al* (2014). Quantitative studies are also not immune to recruitment bias (Stratton, 2015). Practical measures such as using a contact to deliver surveys as reported by van Bruchem-van de Scheur *et al* (2008a), can also lead to sample bias.

Non-response bias (Gray, 2014) is also an issue in assisted dying survey research. Non-response error occurs when sampled individuals do not answer questions or parts of questions, or fail to respond (Stratton, 2015). Challenging the representativeness of the sample Rosenfield (2000) suggests that non-responders in assisted dying research may object to its practice and have differing, but unheard, views or experiences. Several appraised papers acknowledge this problem (Ganzini *et al*, 2000; van Bruchem-van de Scheur *et al*, 2008a; Carlson Simopolous, Goy, Jackson and Ganzini, 2005). Ganzini *et al* (2000) also suggest that doctors, uncertain about or opposed to assisted dying, give less information on a case-by-case basis. Secondary samples drawn from earlier research studies, such as Inghelbrecht *et al's* (2010) survey of Belgian nurses' experiences with their own non-response bias, may exacerbate this problem.

### 2.7.3 Reuse of Questionnaires

Questionnaires in assisted dying studies are often reused, albeit with some adaptations. Sometimes adaptations are made to facilitate a survey's use with other staff groups. For example Ganzini *et al's* (2002) survey assessing the experiences of nurses and social workers, also reported by Miller *et al* (2004), adapted a questionnaire originally designed for medical staff (Ganzini *et al*, 2000). Questionnaires for nurses have also been adapted. This includes van Bruchem-van de Scheur *et al* (2008a) Dutch survey. This was adapted for use in Belgium (Inghelbrecht *et al*, 2010) which, in turn, was adapted for another study by Francke *et al* (2016) in the Netherlands.

Questionnaire design is time-consuming and the reuse of surveys may allow longitudinal comparison (Stratton, 2015). However, reuse may perpetuate the exploration of similar issues instead of uncovering new insights. Particularly in nursing, it sustains a focus on nurses' involvement in requests, decision-making and the administration of drugs (van Bruchem-van de Scheur *et al*, 2008a; Inghelbrecht *et al* 2010; Francke *et al*, 2016). Although some of these surveys (for example, van Bruchem-van de Scheur *et al*, 2007), also included open-answer items which were coded, counted and subject to numerical analysis, it is not clear how they influenced the findings (van Bruchem-van de Scheur *et al*, 2007). Other surveys (Francke *et al*, 2016) included 'self-developed' items.

These may have allowed some freedom in response (Francke *et al*, 2016), but nonetheless, they are directed towards involvement in decision-making and end-of-life actions.

## **2.8 Narrative Review of Themes**

This narrative review (Dixon-Wood *et al*, 2004) will summarise the main themes of the appraised papers within their professional groups of doctors, nurses and therapists. What is known about the experience of Dutch professionals is considered first, in each professional group, as they are most relevant to this study. This is followed by relevant papers for the same professional group from other jurisdictions such as Oregon and Belgium.

### **2.8.1 Doctors' Experiences in the Netherlands**

Table 5 overleaf illustrates the six themes derived from the appraised papers of Dutch doctors' experiences. All the included papers, for doctors, are qualitative in paradigm. The themes focus on their personal struggles related to participation, the importance of the patient's family and the doctor-patient relationship, the nature of requests and the emotional impact of cases.

**Table 5: Summary of Themes: Doctors' Experience in the Netherlands**

<b>Theme</b>	<b>Source of Theme</b>	<b>Description</b>
Personal Struggles	van Marwijk <i>et al</i> (2007); Georges <i>et al</i> (2008)	Doctors felt the dilemma of whether or not to participate and some declined due to religious beliefs. Although seen as part of the modern role, for some doctors, it represented untoward pressure. Some doctors became more reluctant as they became more experienced and older.
The Nature of Requests	Norwood (2007); Borgsteede <i>et al</i> (2007); Georges <i>et al</i> (2008); Snijdewind <i>et al</i> (2014)	Patients usually initiated requests with doctors being open to consideration of requests, but cautious. Patients needed to be able to answer 'why?' Some doctors enhanced care quality to avoid requests which were expressed in decision-making dialogue about end-of-life, as a treatment option, or as a threat of suicide if declined.
The Importance of the Doctor-Patient Relationship	Norwood (2007); Borgsteede <i>et al</i> (2007); Voorhees <i>et al</i> (2014); Snijdewind <i>et al</i> (2014)	The quality of the doctor-patient relationship was important to doctors including any previous care experience with the patient. A lack of openness and relational growth sometimes leads to request rejection. Refusal could affect the relationship.
The Role of Families	van Marwijk <i>et al</i> (2007); Norwood (2007); Snijdewind <i>et al</i> (2014)	Patients' families are influential in the process and outcome of requests. Some families were supportive of the patient and expressed gratitude, but they could also stop requests, apply pressure on doctors and be manipulative.
Emotional Impact	van Marwijk <i>et al</i> (2007); Georges <i>et al</i> (2008); Voorhees <i>et al</i> (2014)	Strong emotions could occur at the first experience including tension before, loss during and relief afterwards, but an inability to share emotions led to loneliness. Coping strategies included taking time out and sharing feelings, but suicidal ideations also occurred.
The Role of Palliative Care	van Marwijk <i>et al</i> (2007); Georges <i>et al</i> (2008)	Education in end-of-life care did not influence doctors' approach to communication with patients requesting an assisted death. There might be more active discussion of palliative sedation. Doctors with a restrictive attitude considered morphine and sedation as an alternative. Doctors working for the Support and Consultation service were more likely to discuss palliative care.

### 2.8.1.1. Personal Struggles

Using focus group data van Marwijk, Haverkate, van Royen and The (2007) identified conflicting personal struggles for doctors. Whilst some doctors considered participating in assisted deaths a “*duty*” (p. 612), for others it represented a modern, but unwelcome role. Some younger doctors had yet to make up their minds whether or not to comply with requests. Over time older, and more experienced doctors, became less keen to participate. Some stopped altogether (van Marwijk *et al*, 2007), but cited patients as being understanding of their decision.

In Georges, The, Onwuteaka-Philipsen and van der Wal’s (2008) interview study, three of 30 doctors declined to assist such deaths because of religious beliefs. A further three declined because of personal uncertainty about their coping ability. This was however, a surprisingly low figure in a study which recruited doctors with a restrictive attitude (Georges *et al* 2008, p.150) towards assisted dying. Doctors used palliative care to improve life’s quality, and sometimes gave large doses of morphine to relieve ‘suffering’. The authors did not consider any broader issues such as the impact on patients of request refusal or consultation with other healthcare staff. Voorhees *et al* (2014), however, suggests that request refusal can strain relationships between the patient and staff.

### 2.8.1.2 The Nature of Requests

Assisted dying requests were initiated by patients themselves (Borgsteede *et al*, 2007; Voorhees *et al*, 2014) but, if aided by a legal framework, doctors sometimes started the dialogue (Voorhees *et al*, 2014). A doctor's approach to a request was dependant on their opinion of assisted dying (Georges *et al*, 2008), but opposed doctors (Georges *et al*, 2008) were open to considering requests.

Patients framed requests by voicing situations when they might consider an assisted death (Norwood, 2007) or made vague statements suggesting they were considering assisted dying (Borgsteede *et al*, 2007). Even if patients had a religious affiliation, sometimes they wanted to discuss assisted dying as an option (Borgsteede *et al*, 2007). Occasionally requests included threats of suicide if an assisted death was not permitted (Snijdewind *et al*, 2014). Seen as blackmail the right to request, but not demand, was seen as an important principle by doctors (Voorhees *et al*, 2014). Norwood (2007) however, highlights that many initial requests only form the basis of 'euthanasia talk' in which doctors clarify procedures and address any misunderstandings. A minority of requests proceed beyond this stage, but patients need to say why they consider euthanasia to be justified, in a socially acceptable fashion, for a request to proceed (Norwood, 2007).

### **2.8.1.3 The Importance of the Doctor-Patient Relationship**

The quality of the doctor-patient relationship was considered important in several studies (Norwood, 2007; Voorhees *et al*, 2014; Snijdewind *et al*, 2014). Professional relationships impacted on request progression (van Marwijk *et al*, 2007; Voorhees *et al*, 2014) and a strong relationship led to more open discussions (Voorhees *et al*, 2014). For doctors, relationship development with the patient during assessment was cited as important (Norwood, 2007; Snijdewind *et al*, 2014). Both Norwood (2007) and Snijdewind *et al* (2014) highlighted the detrimental effect a lack or absence of relational growth had on requests, with refusal by the doctor much more likely.

### **2.8.1.4 The Role of Families**

Several papers suggest that families have a key role in assisted dying (Norwood, 2007; van Marwijk *et al*, 2007; Snijdewind *et al*, 2014), although their influence in official guidance for doctors is understated (Royal Dutch Medical Association, 2011). Doctors' views, in Snijdewind *et al* (2014) paper, illustrate the importance of family in decision-making. They also report that the family's wishes can sometimes take precedence over the patient's wishes if a doctor feels the family may not cope with a hastened death (Snijdewind *et al*, 2014). Some doctors stated their opposition to a request on these ground (Snijdewind *et al*, 2014) and gave the patient their reasons. Norwood's (2007)

ethnographical study, goes further suggesting families can form an integral part of assisted dying conversations with doctors. Doctors also acted as a facilitator between patients and their families, orchestrating dialogue after a request (Norwood, 2007).

Norwood (2007) also highlights the influence of religion which, in some cases, was used by the family to block a patient's assisted dying request. Despite previously strong Catholic and Protestant movements in the Netherlands, the influence of religion declined in the early twentieth century (Kennedy, 2012). However, in 2016, 51% of Dutch citizens were affiliated to a Church (CBS Statistics Netherlands, 2016) with 24% being Roman Catholic. In Norwood's (2007) study, such beliefs were used by families to impede the progress of requests, although the patients themselves exhibited signs of ambivalence, perhaps not wishing to upset their relatives.

Families could be supportive and committed, but could also be manipulative (van Marwijk *et al*, 2007). Van Marwijk *et al* (2007) suggest that sometimes doctors were put in awkward positions regarding which family members are present at the death and whether or not cases should be officially reported. Not all the cases in this paper occurred after the current Euthanasia Act (TLRAS, 2002) and the reporting of cases was optional. As reporting is now mandatory

(TLRAS, 2002) this potentially reduces the usefulness of the findings for contemporary researchers. Conflict situations in families were also reported (van Marwijk *et al*, 2007), but it is unclear what was the cause of the conflict. This study however, is incomplete as an unspecified amount of data was lost due to the theft of a video recording of a focus group.

### **2.8.1.5 Emotional Impact**

Assisted dying is still a relatively rare event in clinical practice. Consequently doctors often lack extensive experience (van Marwijk *et al*, 2007). First cases could evoke however, a strong emotional response (van Marwijk *et al*, 2007). This included tension before the event, loneliness during the process and a sense of loss at the death, but relief afterwards. Voorhees *et al* (2014) also identifies that doctors can experience intense emotions during discussion with patients about assisted deaths. Such emotions can be positive if seen as helping the patient, but were sometimes negative due to the potential for emotional exhaustion (Voorhees *et al*, 2014). Moreover, sharing these feelings with others could be difficult (van Marwijk *et al*, 2007).

Particularly noteworthy is that suicidal ideations (Kelly and Varghese, 2006) also occurred. A doctor who only performed assisted deaths on patients she knew well tasted a lethal drug before entering the home thinking "*if I drink this potion now, it's all over*" (van Marwijk *et al*, 2007, p.611). Other papers suggest

some doctors are unable to continue to work after an assisted death due to emotional exhaustion for example, Georges *et al* (2008).

### **2.8.1.6 The Role of Palliative Care**

Controversy surrounds the relationship of palliative care to assisted dying (Borgsteede *et al*, 2007). Practically however, in a study of doctors who had undertaken end-of-life care education, and those who had not (Borgsteede *et al*, 2007), training did not affect their approach to dialogue about assisted dying with patients. Van Marwijk *et al* (2007), however, suggested doctors working for the Support and Consultation Service (Royal Dutch Medical Association, 2011) cited palliative care more frequently than other doctors. This may be due to their mandatory training but, as noted above, data analysis was incomplete due to loss of video footage. Active discussion of palliative sedation is reported by van Marwijk *et al* (2007) and Voorhees *et al* (2014). Georges *et al* (2008), however, cited using palliative sedation and large opioid doses as an alternative to euthanasia, but the stated intention of this action was not to cause death.

### **2.8.2 Experiences of Doctors in Oregon**

Three included papers focus on (Ganzini *et al*, 2000; Dobscha, Heintz, Press and Ganzini, 2004), or include (Voorhees *et al* 2014), the experience of Oregonian

doctors (Summary Table, Appendix 4). These studies are informative and highlight the nature of doctors' interventions and their perceptions of patients and families. The themes arising are shown below in Table 6. These themes, as explored below, differ from those related to Dutch doctors' experiences shown previously in Table 5.

**Table 6: Summary of Themes: Oregonian Doctors' Experiences**

Source of Theme	Theme	Description
Ganzini <i>et al</i> (2000); Voorhees <i>et al</i> (2014)	Doctors Interventions	Doctors dealt with questions and instigated a range of medical interventions related to end-of-life and assisted dying. These included seeking a second opinion and a mental health review if appropriate. Difficulties were experienced in gaining a second medical opinion and obtaining lethal drugs with concerns about the doctor and the patient's privacy. Interventions sometimes altered the mind-set of patients.
Dobscha <i>et al</i> (2004); Voorhees <i>et al</i> (2014)	Impact of Discussions and Actual Requests	Dialogue about assisted dying and dealing with requests was emotionally intense. Some doctors were apprehensive and others avoided it, but it could also be rewarding.
Dobscha <i>et al</i> (2004); Ganzini <i>et al</i> (2003)	Doctors Perceptions of Patients and Families	Patients tended to be independently minded, forceful and persistent in their request with a desire to stay in control. Some, but not all, families were supportive.

The experiences of Oregonian doctors has been Included here for completeness, but some caveats need to be considered. Firstly, the Death with Dignity Act of Oregon (Oregon Health Authority, 2017) differs significantly from the Dutch Euthanasia Law (TLRAS, 2002), particularly for doctors. Notably, in

the United States, self-administration of lethal drugs by the patient is the only form of assisted dying permitted. Prescribing doctors are not required to be present at death although some may choose to attend (Dobscha *et al*, 2004). Euthanasia is prohibited.

This potentially invalidates direct comparison of Dutch and American doctors' experiences, but some commonalities can be seen. Notably, requests and dialogue about assisted dying generated a range of emotions including discomfort, surprise, an obligation to optimise care, and not to abandon patients. Dobscha *et al*'s (2004) qualitative paper also reported the characteristics of assisted dying patients, as perceived by their doctors, who admired their tenacity, wit and determination. In a paper based on the same data, Ganzini, Dobscha, Heintz and Press (2003) add other adjectives such as 'memorable', 'reclusive' and 'demanding'. Large scale survey research by Ganzini *et al* (2000) is also informative, identifying the range of interventions undertaken by American doctors including control of symptoms and referral for a mental health or spiritual assessment which sometimes changed the mind-set of the patient. Unfortunately, there is no comparable survey of Dutch doctors, limiting the use of Ganzini *et al*'s (2000) findings to this study.

### 2.8.3 Nurses' Experiences: Themes

There is limited research related to Dutch nursing, as reported by other researchers (Francke *et al*, 2016). Only two Dutch studies, van Bruchem-van de Scheur *et al* (2008a) and Francke *et al* (2016), both surveys, met the inclusion criteria for this review. Consequently, these papers are considered alongside other relevant empirical papers related to nursing from Belgium (Inghelbrecht *et al*, 2010; Dierckx de Casterlé *et al*, 2010) and Oregon (Ganzini *et al*, 2002). Unlike the experiences of doctors already discussed, and despite variations in the law between jurisdictions (Appendix 1), there are some universal themes shown overleaf in Table 7. These are likely to reflect commonalities in the nursing role across jurisdictions despite variations in assisted dying legislation.

**Table 7: Summary of Themes: Nurses' Experience**

<b>Theme</b>	<b>Source of Theme</b>	<b>Description</b>
Receiving Requests	Ganzini <i>et al</i> (2002); van Bruchem-van de Scheur <i>et al</i> (2008a); Dierckx de Casterlé <i>et al</i> (2010)	Nurses received assisted dying requests from patients, sometimes when they are being expressed for the first time. Key skills included listening with an open mind and a non-judgemental attitude before discussing with colleagues and the wider healthcare team.
Involvement in Decision-Making	Ganzini <i>et al</i> (2002); van Bruchem-van de Scheur <i>et al</i> (2008a); Dierckx de Casterlé <i>et al</i> (2010); Inghelbrecht <i>et al</i> (2010); Francke <i>et al</i> (2016)	Nurses were often involved in decision-making whether or not they are required to be consulted in law. Consultation was more frequent in hospitals and nursing homes for Dutch nurses than home care. The Belgian law requires nurses to be consulted, but this was more likely in settings with multidisciplinary care. Nurses valued their voice in decision-making, made time to give the patient and family explanations, but did not always agree with the final decision made.
Involvement in the Assisted Death	van Bruchem-van de Scheur <i>et al</i> (2008a); Dierckx de Casterlé <i>et al</i> (2010); Inghelbrecht <i>et al</i> (2010); Francke <i>et al</i> (2016)	Nurses prepared for the death by paying special attention to the patient and family, and give extra care. They prepared infusions, the care environment and met final requests. They said goodbye to the patient. Nurse administration of lethal drugs is illegal, but there is some evidence that it occurred. Such actions might be to aid the doctor, but the actual reasons were unknown.
Aftercare	Dierckx de Casterlé <i>et al</i> (2010)	The family were given time with the deceased before laying out procedures. Nurses answered questions about what to tell children or other people. They found it important to pay their last respects to the patient. Nurses contacted the family after the death for a bereavement support conversation or to invite them to memorial services.

### 2.8.3.1 Receiving Requests

A national survey by van Bruchem-van de Scheur *et al* (2008a) reviewed the assisted dying role of nurses in hospitals (van Bruchem-van de Scheur *et al*, 2008b), home care (van Bruchem-van de Scheur *et al*, 2007) and nursing homes. Regarding requests, in 37% of cases analysed, a patient spoke to a nurse first about assisted dying. There were, however, variations across care settings, with nurses in hospitals (45.1%) and nursing homes (44.3%) more likely to receive requests than home care nurses (22.3%) (van Bruchem-van de Scheur *et al*, 2008a). This may be because Dutch patients at home are likely to have a family doctor with whom they have a long-standing relationship (Norwood, 2007).

Qualitative research by Dierckx de Casterlé *et al* (2010) adds depth to these findings, suggesting formal requests are rarely a surprise to nurses. Why this is so is not fully explored, but nurses considered requests in an open and non-judgement manner. Being attentive and understanding the patient's reasoning were considered important, with serious requests being forwarded to the wider healthcare team (Dierckx de Casterlé *et al*, 2010).

### 2.8.3.2 Involvement in Decision-Making

Nurses were often involved in decision-making, with consultation between Dutch doctors and nurses common, taking place in 65.9% of cases (van Bruchem-van de Scheur *et al*, 2008a), but a wide variation between settings is evident. In home care, for example, it was less common (41.2%) than in hospitals (78.8%) and nursing homes (81.3%). This may reflect working practices, as Dutch home care nurses often work from premises away from the family doctor's surgery (van Bruchem-van de Scheur *et al*, 2007) and therefore, were not readily available. As the majority of assisted deaths, however, will occur at home (Royal Dutch Medical Association, 2017) this suggests the decision-making in many cases may not benefit from nurses views.

Where consultation does occur though, in the majority of home cases (87.9%), nurses agreed with doctors' decisions (van Bruchem-van de Scheur *et al*, 2007). Nurses' disagreements with a doctor's decision across all care settings (van Bruchem-van de Scheur *et al*, 2008a) related to conscientious objection, the patient's condition not being serious enough, or to a lack of evidence of unbearable suffering (van Bruchem-van de Scheur *et al*, 2007). This study did not explore however, the feelings of nurses if they disagreed with the doctor's decision. Disagreement however, was more likely for refused requests (van Bruchem-van de Scheur *et al*, 2008a) which the authors suggest may reflect the nurses' empathy with the patient.

### 2.8.3.3 Involvement in an Assisted Death

Survey research related to assisted dying and nursing often includes the administration of lethal drugs (van Bruchem-van de Scheur *et al*, 2008a; Inghelbrecht *et al*, 2010; Francke *et al*, 2016). An exception is Ganzini *et al*'s (2002) study which included Oregonian nurses. This probably reflects legal differences as in the United States lethal drugs need to be self-administered by the patient. Van Bruchem-van de Scheur *et al*'s (2008a) Dutch study however, highlighted that in five cases (3.5%) nurses delivered lethal drugs or aided a doctor to do so (11.9%). This constitutes an illegal act which can lead to prosecution or removal from the BIG Register, the national register for Dutch doctors, nurses and other health care professionals (CIBG, 2017). Guidance for Dutch nurses has been strengthened (Vossen, 2007), but in a recent survey (Francke *et al*, 2016) 7% of 587 nurses thought they were legally able to administer lethal drugs. An incorrect assumption, this suggests that the passage of time alone may not embed key legal principles. Surveys may however, lack the sensitivity to determine understanding, and to accurately report complex actions (Stratton, 2015).

In comparison, qualitative research such as Dierckx de Casterlé *et al* (2010) is more informative about the nursing activities undertaken at an assisted death. As well as preparing infusions for drug delivery, nurses organised the room to accommodate family members and the doctor, explained procedures to the

patient and family, and carried out the patient's final requests. This study notes that such deaths can be emotional for nurses who may cry or pray with the family (Dierckx de Casterlé *et al*, 2010).

#### **2.8.3.4 Aftercare**

Consideration of after-death care is rare with the exception of Dierckx de Casterlé *et al's* (2010) study. Family members spent time with the patient before laying out procedures. After assisted deaths nurses might deal with additional questions such as queries about explaining the death to children or other people. Dierckx de Casterlé *et al* (2010) also reported some bereavement care which involved contacting the family for a conversation or to invite them to a memorial service.

#### **2.8.4 Experiences of Therapists**

The term therapist as, used in this study, is defined in Chapter One (1.7), but studies related to therapists' experiences of assisted dying are limited. This review failed to find any Dutch papers. Five papers from the United States met the inclusion criteria, but after the removal of duplicate papers and quality appraisal (Summary Table, Appendix 4) only two surveys and one qualitative study remained. These focus on Oregonian social workers (Ganzini *et al*, 2002;

Norton and Miller, 2012) and chaplains (Carlson *et al*, 2005). Limited to hospice affiliated staff the questionnaire designs are based on surveys used with nurses and doctors (Ganzini *et al*, 2000; Ganzini *et al*, 2002). A single focus group is the source of data for the qualitative paper (Norton and Miller, 2012).

#### **2.8.4.1 Involvement in Assisted Dying**

Ganzini *et al* (2002) and Carlson *et al* (2005) provide information on social workers' and chaplains' involvement. In Ganzini *et al*'s (2002) survey isolating the activities of social workers and nurses is difficult due to the amalgamation of data. This data presentation might be to protect nurses whose professional associations are opposed to their participation in assisted dying (American Nurses Association, 2013). Social workers however, initiated conversations about assisted dying. In this activity they were more comfortable than nurses perhaps reflecting their greater professional autonomy (Ganzini *et al*, 2002).

Norton and Miller's (2012) qualitative study however, highlighted that hospice social workers often lacked clarity regarding their role and worked in institutions with policies that limited their involvement. Colleagues were also not always willing to support patients with referral to advocacy organisations the most expedient method of patients gaining timely advice. A small number of social workers also attended assisted deaths sometimes in violation of their

hospice policy (Norton and Miller, 2012). A high proportion of social workers (95%) (Ganzini *et al*, 2002) endorsed the continuing care and support of hospice patients despite their choice of an assisted death.

Similarly in Carlson *et al*'s (2005) survey (Summary Table, Appendix 4), 54% of Oregonian chaplains, affiliated to Protestant (78%), Roman Catholic (16%) and other (6%) denominations, had counselled a patient who chose an assisted death with 36% also ministering. Conversations with the patient related to the role of faith and spirituality in the patient's decision-making, their reasons for wanting an assisted death and concerns about family or their reactions (Carlson *et al*, 2005). Chaplains suggested that such relationships were aided by non-judgemental support, a prior relationship with the patient, or the patient having a previously helpful clergy relationship. Chaplains who actively opposed assisted dying were significantly less likely to see such patients, but overall chaplains did not believe they strongly influenced patients (mean score 4.0 on a 0-10 scale) suggesting that patients had already made up their minds.

## **2.9 Summary of Chapter**

A systematic approach (Kable *et al*, 2012) to searching for literature has aided the identification, appraisal and critical review of empirical papers relevant to the care experience of assisted dying for doctors, nurses and therapists. Papers

have been sought from jurisdictions with permissive legislation with data collection from the time of its implementation. This time frame was expanded for Dutch papers as many related to a legal transition zone between pre-existing practice and the Euthanasia Act of 2002 (TLRAS, 2002).

Research into the assisted dying experience of staff exists, but studies vary in quantity, methodology and quality in relation to medicine, nursing and therapies. Relevant Dutch papers in medicine and nursing often relate to a time of transition in assisted dying policy (Norwood, 2007; Borgsteede *et al*, 2007; Georges *et al*, 2008; van Bruchem-van de Scheur *et al*, 2008a) and include data collected prior to the 2002 law (TLRAS, 2002). This might not, however, reflect issues experienced by staff post-legislation and staff perceptions of their experiences may now differ.

Qualitative research is available related to the experience of Dutch doctors. These studies however, often focus on a single dimension such as communication (Borgsteede *et al*, 2007), dealing with requests (Georges *et al*, 2008) or the emotional experience (van Marwijk *et al*, 2007) rather than exploring assisted dying along a care trajectory from an initial request to beyond bereavement. Themes arising from these papers however, include the doctor's personal struggles, the nature of requests, the importance of the doctor-patient relationship, the role of families, the emotional impact and

palliative care. Additional information can be extracted from American studies, but its value may be limited due to differences in the legislation. It has been added for completeness.

Research relating to Dutch nurses is very limited and only quantitative studies (van Bruchem-van de Scheur *et al*, 2008a; Francke *et al*, 2016) have been found. This is supplemented by research from other jurisdictions. This includes papers from Belgium (Dierckx de Casterlé *et al*, 2010); Inghelbrecht *et al*, 2010), where assisted dying legislation is similar to the Netherlands, and one study from the United States (Ganzini *et al*, 2002) for completeness. Themes arising from the nursing papers include receiving requests, nurses' involvement in decision-making, the administration of drugs, the death and aftercare.

Literature searches have been unable to find research related to experiences of Dutch therapists. There is however, relevant literature from the United States on social workers (Ganzini *et al*, 2002; Norton and Miller, 2012) and chaplains (Carlson *et al*, 2005) and this is included.

This comprehensive critical appraisal of relevant studies has identified the incomplete nature of our knowledge of the staff experience of assisted dying. Research related to doctors is the most plentiful, but studies often focus on limited aspects of their experience, predetermined in survey research.

Qualitative studies often relate to an historic time, a transition zone immediately before and after the 2002 law. This may not reflect more recent staff experiences. In some qualitative studies there are also unresolved methodological issues. A quantitative survey of Dutch nurses (van Bruchem-van de Scheur *et al*, 2008a) relies on data gathered in the legal transition zone. Reuse of this questionnaire has also resulted in similar themes arising in later nursing studies. At the time of completion, the literature review identified a lack of qualitative studies related to the experience of Dutch nurses. It also failed to uncover any studies related to Dutch therapists' experiences, a single theme being derived from American studies. To address these gaps this study utilises qualitative methodology and methods, with a constructivist philosophy, to gain a view of the experiences of doctors, nurses and therapists along a clinical trajectory from an assisted dying request to beyond the death.

# Chapter Three: Methodology and Methods

## 3.1 Introduction

The aim of this study was to gain an understanding of the experience of Dutch healthcare staff of assisted dying from an initial request through, in some cases, to bereavement care. The research question is:

*'What is the experience of assisted dying for Dutch healthcare staff working in a hospice or a chronic disease care centre?'*

The theoretical approach to answer the research question and the rationale for the methodological decisions made in the design, and implementation of the study, are presented in this chapter.

To establish the reasoning behind the choice of a constructivist interpretative approach (Lincoln and Guba, 1985) this chapter starts with a short review of research paradigms and their philosophies. A review of the tenets of constructivist enquiry is followed by the characteristics of qualitative research, and the justification for its use in this study. The qualitative methods used in this study are identified including sampling and recruitment, data collection and analysis, and the controversies surrounding *rigor* in qualitative research are included (Morse, 2015). The ethical principles and procedures considered prior to, during, and in the dissemination phase of the study complete the chapter.

## 3.2 Research Paradigms and Philosophies

Methodology is described as the “*the analysis of, and the broad philosophical and theoretical justification for, a particular [research] method*” (Gray 2014, p.686). Underpinning the choice of any research method, are philosophical assumptions about the legitimacy of knowledge (epistemology) and the nature of reality (ontology) (Patton, 2015).

### 3.2.1 A Brief Historical Review

Social, political, cultural and economic changes in the 17th century (Snape and Spencer, 2003) and disenchantment with religion as a solution to theodicy (evil), led to the emergence of the natural sciences (Jovanović, 2011).

Observational experimentation and inductive reasoning, such as advocated by Francis Bacon (Crotty, 1998) and Isaac Newton (Hammersley, 2013), became a means of acquiring certainty beyond theology and speculation (Jovanović, 2011). August Comte (1798-1857) called such empirically acquired knowledge as ‘positive’ (Patton, 2015) leading to the popularisation of the term ‘positivism’ (Crotty, 1998), a term for research which generates laws, or ‘truths’, that operate across time and place (Hammersley, 2013). Creating such laws requires the measurement, often of large numbers of cases and the control of variables. The desire for an objective appraisal of the phenomenon, however, can also result in the dismissal of individual intuitions and expertise

(Hammersley, 2013) alongside a lack of recognition of any contextual influences.

What is considered a fact or 'truth' (Weinberg, 2002) however, may take many forms (Lincoln and Guba, 1985). Challenges to positivism and its domination as the only form of valid knowledge arose in the early decades of the 20<sup>th</sup> century (Jovanović, 2011). These challenges came from a variety of sources including George Herbert Mead in American psychology and the German social scientist Maximilian Weber (Bryman, 2016), but there were also influential academics in London (Malinowski) and France (Durkheim) (Jovanović, 2011). Notably, the assumption that positivist scientific exploration will always uncover all facets of a phenomenon was challenged (Weinberg, 2002). Instead a new value was placed on the subjective point of view as a means of gaining a deeper understanding of the ontological reality of an experience or other topic (Snape and Spencer, 2003).

A 'renaissance' of qualitative inquiry is reported as occurring in the 1960s (Jovanović, 2011), but as this terminology suggests, it had an earlier conception. The first incarnations of a new flexible, data-driven (Hammersley, 2013) approach to inquiry occurred in the opening decades of the 20<sup>th</sup> century. Most notably in Chicago, research arising from the University's School of Sociology (Bulmer, 1984) sought to gain a deeper understanding of the lived experience of migrant populations. Seminal works included Thomas and

Znaniecki's study of Polish migrants (Thomas and Znaniecki, 1918-20) which used case studies, and personal documents such as letters and interviews, with the aim of gaining a personal and contextualised meaning (Jovanović, 2011).

At the same time Weber (1864-1920) explored the nature of *Verstehen* (Crotty, 1998). Often translated into 'understanding' Weber's use of this German term is narrower than its translated meaning (Bryman, 2016), but he identified differing levels of 'understanding'. At the first level, direct observation of an action may lead to a rational understanding of a phenomenon (Snape and Spencer, 2003) as utilised in experiential research. Access to a second level however, is needed to understand individual and collective actions within the context of peoples' lives (Snape and Spencer, 2003). This science of society, or social science, required methods of inquiry that could uncover the motives for people's actions which, in turn, are shaped by socio-historical context, personal and collective values, and culture (Jovanović, 2011).

Accessing such higher levels of understanding required flexible research methods capable of providing an *interpretative* (Bryman, 2016) view of the reality of individuals and their social reality. A new value was placed on the quality (*qualitas*, Latin) of unstructured personal accounts rather than the primary focus being the fixed measurements or collation of amounts (*quantitas*, Latin) (Hammersley, 2013). Subjectivity in values (Jovanović, 2011), instead of being frowned upon, was celebrated (Hammersley, 2013) and seen as an

essential element in conceptualising raw data. Since the 1960s an increasing interest in social science research (Jovanović, 2011) has led to the emergence of alternative research paradigms such as a *constructivism* (Guba and Lincoln, 1989) the philosophical approach that underpins this study.

### **3.3 Constructivism**

Constructivism is a philosophical approach which can lead to action and further steps (Lincoln, Lynham and Guba, 2011) and it has a pedigree in healthcare practice (Pascoe *et al*, 2013; Hussein and Hirst, 2016).

Confusingly, the terms *constructivism* and *constructionism* are often used interchangeably (Thomas, Menon, Boruff, Rodriguez, and Ahmed, 2014; Patton, 2015) so it is necessary to clarify their use here. *Constructivism* focuses on the individual's thought processes in the meaning-making of an experience (Crotty, 1998). All meaning is influenced however, by its social origins (Crotty, 1998) and an individual's experiences and values are embedded in the culture in which they operate. Therefore, in this study, reference is also made to *social constructionism* (Hammersley, 2013). Social construction, largely derived from the work of sociologist Karl Mannheim (Berger and Luckman, 1966), recognises that reality is influenced by the social world in which people operate, but this, in turn, is actively being reshaped by the players within it (Burr, 2015). The climate or culture where people live and work is, therefore, a dynamic phenomenon as opposed to being a fixed set of prescribed practises (Crotty,

1998). As this study focuses on data from interviews with individual staff the term *constructivism* will dominate here. The tenets of constructivism are discussed in 3.3.2.

### **3.3.2 Tenets of Constructivism**

Ontologically, constructivism takes a *relativist* view of the world with multiple social realities (Snape and Spencer, 2003). This contrasts with the *realist* position of positivism which asserts that an external world, governed by fixed, but generalisable laws, can be accessed directly (Crotty, 1998). Instead the *relativist* ontology of constructivism asserts that only a representation of the world is accessible which, in turn, is socially constructed by people (Guba and Lincoln, 1989). 'Truth' is defined as the 'best informed' construction of a phenomenon for which there may be consensus based on the amount, quality, and power of the supplied information (Guba and Lincoln, 1989).

This relativist world view leads to the second tenet of constructivism, its epistemological position, which holds that knowledge is subjective, with any conclusions co-created by researchers and their participants (Guba and Lincoln, 1989). Therefore objectivity, with the distancing of the researcher and the researched, as advocated in positivism, is impossible (Guba and Lincoln, 1989). Crotty (1998) however, cautions against the notion that constructivism is entirely subjective, as phenomena need a tangible element worthy of

exploration. Therefore, subjectivity can be considered on a continuum with objectivity, as espoused in positivism, towards one end and constructivism at the opposite end (Crotty, 1998).

Finally, constructivism requires methodology that is iterative and seeks to explore the truth of options which involves analysis, critique and reanalysis leading to the construction of final conclusions. This may include seeking to understand meaning directly from those who experience the phenomenon using participants in the research process (Lincoln *et al*, 2011). This contrasts with the interventionist methodology advocated by positivism which aims to remove or minimise contaminating influences in order to explore, predict and control (Guba and Lincoln, 1989). In this study, to satisfy the tenets of a constructivist inquiry, qualitative methodology is used.

### **3.3.3 The Characteristics of Qualitative Research**

Accessing the reality of participants in their own world requires methodology capable of empathetic enquiry (Denzin and Lincoln, 2011). Qualitative research meets this demand by employing a set of interpretative practices to make what is hidden visible (Denzin and Lincoln, 2011). A representation of the world is formed from relatively unstructured data (Hammersley, 2013), collected in conversations, interviews, field notes, as visual images, or based on observations (Denzin and Lincoln, 2011).

Some common hallmarks of qualitative research have been identified (Hammersley, 2013; Creswell, 2014). Qualitative research requires a naturalistic approach to data collection (Lincoln and Guba, 1985) which often takes place in ordinary settings such as the workplace or at home (Hammersley, 2013). This is in contrast to laboratory settings, designed to isolate the phenomenon under study, as might be used in positivistic research. Assessing a phenomenon holistically in qualitative study may also require field work, sometimes for prolonged periods of time (Miles and Huberman, 1994). Multiple perspectives are gathered to gain insight and a deeper understanding of the topic under study (Morse, 2011). In qualitative inquiry, like constructivist philosophy, the researcher and topic are inseparable and will influence each other (Lincoln and Guba, 1985) potentially leading to bias. Therefore, to promote rigor in the qualitative research process (Jootun, McGree and Marland, 2009), reflexivity is needed to assess the degree of influence exerted by the researcher.

Attention to context and relatively small sample size (Morse, 2006) render attribution about absolute causation impossible in qualitative study. Some writers, for example Charmaz (2011), however, do advocate generalisability as possible, with the caveat that any claims made are "*partial, conditional and situated*" (p.366). Qualitative findings can also be used, as here, to develop recommendations based on descriptive analysis of a phenomenon (Lincoln and Guba, 1985).

There is however, a counter-argument suggesting the concept of generalisability itself is flawed (Lincoln and Guba, 1985). Study in the social sciences can never be context-free (Silverman, 2010), but qualitative research can reflect the uniqueness of a situation, develop understanding and illuminate differing perspectives (Patton, 2015) such as the assisted dying experience of staff in this study.

### **3.3.4 Use of Qualitative Research in End-of-Life Care**

Qualitative methodologies have been embraced more comprehensively in oncology and palliative care than in other areas of health research (Borreani, Miccinesi, Brunelli and Lina, 2004). Palliative and end-of-life care has utilised qualitative methods since Glaser and Strauss's (1967) work using Grounded Theory and Kübler-Ross's (1970) influential writings on grief. Reviewing its history in end-of-life care research, Timmermans' (2013) highlights the revolutionary use of qualitative study for the exploration of topics in controversial domains. Glaser and Strauss's (1970) research epitomises this, exploring patients' awareness of diagnosis and prognosis at a time when open disclosure by doctors was rare. Social scientists, philosophers and historians have argued that mortality forms the "*ultimate limit*" (Timmermans, 2013, p.21) of empirical exploration in modern societies but, it could be argued, assisted dying research may extend these boundaries even further.

## **3.4 Methods**

### **3.4.1 Population**

Assisted dying is illegal in the United Kingdom. Therefore acquiring insight into staff experiences required travel abroad which, due to the time investment, limited the research to two sites (Vassy and Keller, 2013). Access to research sites abroad is often conducted through professional contacts (Vassy and Keller, 2013) and it was through contacts that it was possible to negotiate access to a chronic disease care (site A) and, later, to a hospice (site B) in the same Dutch city. Although the majority of Dutch assisted deaths occur in primary care (Royal Dutch Medical Association, 2017), for a lone researcher, high numbers of single doctor practices (Eler *et al*, 2011), and the relative rarity of cases made accessing primary care impractical. Of the two organisations permitting access, the chronic disease care centre was the larger with a total of 95 staff while the hospice employed 41 staff.

### **3.4.2 Sampling Strategy**

Qualitative research does not seek statistical significance and, consequently, optimal sample sizes are not definable (Beitin, 2012). The sampling strategy and the sample size focused on collecting data in adequate depth and breadth to answer the research question (Patton, 2015). Data analysis can also be time-consuming with whole population sampling impractical (Wengraf, 2001). Moreover, a random selection of staff would have wasted time and effort (Wengraf, 2001). Therefore, *non-probability purposive sampling* (Robson, 2011) was used to recruit doctors, nurses and therapists with experience of patients requesting assisted dying to inform the research from “*multiple angles of vision*” (Thorne, 2008, p.78).

### **3.4.3 Staff Recruitment**

An internal email was circulated to all staff at the hospice and chronic disease care centre (Appendix 6). A Letter of Invitation and a Participant Information Sheet (Appendix 7) were sent to staff who expressed an interest. A doctor and nurse at the chronic disease care centre (site A) and a hospice nurse manager (site B) circulated information and booked an interview room. The potential for an imbalance of power between the researcher and the participant (Cook, 2012), discussed in 3.4.4, needs to be considered at the recruitment stage (Kelly, 2013), but in this study participants were approached indirectly. As I was

a non-staff member, they were also able to decline participation without sanctions.

The biographies of the recruited staff including their professional group, with general and assisted death experience, are shown in Appendix 8. Occasionally, a participant had experience relevant to more than one professional group, for example a hospice therapist [P1] who also held nursing qualifications. The participant was allocated to the therapist professional group as it was most appropriate to her current job description. Another participant [P12] initially stated her role on the unit as nursing, but at interview further exploration highlighted that she worked in a voluntary capacity as she had retired from nursing. In this capacity she did however, fulfil a specific role at the time of assisted deaths and was therefore, also allocated to the therapists group. In total twenty-one staff were recruited (Table 8) from three professional groups across the two research sites.

**Table 8: Staff Recruited by Site and Designation**

Site	Staff Recruited
<b>Site A</b> <b>Chronic Disease</b> <b>Care Centre</b> [CDCC] 95 Staff	Doctors [x 6], Nurses [x 5]  Social Worker [x 1], Physiotherapist [x 1], Speech and Language Therapist [x 1], Creative Therapist [x 1], Volunteer [x 1]
<b>Site B</b> <b>Hospice [H]</b> 41 Staff	Hospice Doctor [x 1], Nurse Ward Manager [x 1], Nurses [x 2] Activities Organiser [x 1]

### **3.4.4 Data Collection**

As direct observation was impractical semi-structured face-to-face interviews were used to collect data. This is a useful method of accessing the perspective others (Patton, 2015) when the focus of enquiry is a potentially sensitive topic (Fontana and Frey, 2005). End-of-life care is complex and to ensure a focus on issues related to the research question, an interview guide (Appendix 9) was used. This also helped to explore the same line of enquiry with each staff member (Patton, 2015) including experience and behaviour questions, opinion questions, and questions relating to feelings. Questions constructed were informed by the literature review (Rapley, 2004), reading around the topic area, and talking to staff on a previous visit. The interview process was iterative, with issues identified with other participants explored, and a flexible approach taken to allow staff to expand issues important to them.

Interviews are a social encounter (Warren, 2012). Therefore they are subject to socially constructed influences such as power imbalances due to gender, race, ethnicity, class and education (Kelly, 2013). The surroundings in which they are conducted may also have an influence (Kelly, 2013). To aid staff comfort, interviews were conducted in familiar surroundings on-site at the hospice and chronic disease care centre, but to ensure anonymity the interview rooms were sited away from the clinical area. Care was taken to build rapport at the start of the interview (Patton, 2015), to be sensitive to any interruptions such as radio

paggers, and to be non-judgemental of the responses. Probing (Patton, 2015) and gentle nudging (Rapley, 2004) of dialogue was occasionally needed, but care was taken not to introduce bias such as agreeing with a stance on assisted dying. Sometimes, after disclosures that were emotional, participants needed a period of silence to collect their thoughts and this was respected (Warren, 2012). Interviews were digitally recorded (Kelly, 2013), but if staff offered insights after recording had stopped (Bryman, 2016), notes were signed by the participants to consent to their use (Vogt, Gardner and Haeffele, 2012).

#### **3.4.4.1 Cross-National Interviews**

This is a cross-national study defined by Mangen (1999) as “*analysis undertaken by a non-native*” (p.109). English is spoken by over 80% of the Dutch population (van Oostendorp, 2011) and all the interviews were conducted in English. Ethical approval for the study did include the use of translators, but this proved unnecessary. Written notes were taken with one staff member whose English was less fluent, but the interview was of sufficient quality for analysis. Despite the generally high standard of English spoken for some roles, as noted by Vassy and Keller (2013), a direct translation is not always possible. Questions and ideas may also have to be simplified by the interviewer. For the participants, speaking in a foreign language can be tiring; this limits the interview length, and potentially, the depth of exploration of issues. Despite the challenges, Patton (2015) reminds us that cross-national

interviews are likely to be superior in achieving a deeper understanding of the perspectives of others when compared to using a survey, but they may be less in-depth than interviewing in the participant's native language.

### **3.4.5 Data Analysis**

Qualitative methods generate large amounts of data. Several thematic analysis conventions exist (Ritchie, Spencer and O'Connor, 2003; Bryman, 2016) usually designed to move the data "*beyond the self-evident*" (Thorne, Kirkham and O'Flynn-Magee, 2004, p.5). Here, Braun and Clarke's (2006) six-phase approach, as utilised in other healthcare studies (Bonnington and Rose, 2014), was applied to manage, describe, and interpret the data (Crowe, Inder and Porter, 2015). Table 9 overleaf illustrates Braun and Clarke's (2006) six phases. This is followed by a detailed description of each phase which includes signposting to illustrative appendices.

**Table 9: Applying a Six Phase Approach to Thematic Analysis. Adapted from Braun and Clarke (2006)**

Phases 1 to 6	Action
1. Familiarisation with data	<ul style="list-style-type: none"> <li>• Self-transcription of interviews</li> <li>• Time-dated transcript produced including the questions posed, colloquiums, prompts, pauses and expressions of emotion</li> <li>• Transcripts checked against digital recordings for accuracy and coherence</li> </ul>
2. Generating initial codes	<ul style="list-style-type: none"> <li>• Repeated review of transcripts</li> <li>• Identification of significant data extracts</li> <li>• Collation of data extracts with common themes</li> <li>• List of initial codes</li> </ul>
3. Searching for potential themes	<ul style="list-style-type: none"> <li>• Identification of potential candidate themes</li> <li>• Naming of candidate themes</li> <li>• Identification of outlining issues</li> </ul>
4. Reviewing themes	<p>Level 1:</p> <ul style="list-style-type: none"> <li>• Iterative reduction of themes by code comparison</li> <li>• Subthemes identified, named and allocated to main themes</li> </ul> <p>Level 2:</p> <ul style="list-style-type: none"> <li>• Consider theme validity over data set</li> <li>• Removal of candidate themes not relevant to the research question</li> </ul>
5. Defining and naming themes	<ul style="list-style-type: none"> <li>• Identify essence of each theme and collate evidence.</li> <li>• Identification of latent themes for further interpretation and analysis</li> </ul>
6. Writing the report	<p>Final report writing [Chapter 5: Discussion Chapter ]</p> <ul style="list-style-type: none"> <li>• Discussion of new insights or novel themes</li> <li>• Discussion of latent themes</li> </ul>

### **3.4.5.1 Phase 1: Familiarisation with the Data**

Self-transcribing audio-recordings (Silverman, 2010) aided the start of the interpretative process (Braun and Clarke, 2006). The verbatim transcripts included pauses, interruptions, prompts (Rapley, 2004), with the participants' emotions such as anger or distress, if expressed, in brackets. Questions posed by the interviewer are crucial in establishing the context of responses (Potter and Hepburn, 2005) and were included in transcripts. Transcripts were reread, checked for accuracy against original recordings, with Dutch words translated using a Dutch-English dictionary (Osselton and Hempelman, 2003), to produce a coherent account. Listening, checking and rechecking also helped to contextualise the language used by staff (Kelly, 2013). Where directly equivalent roles did not appear to exist the most appropriate used translation was chosen.

### **3.4.5.2 Phase 2: Generating Initial Codes**

Initial codes were generated from listening to the interviews, reviewing the interview transcripts and isolating significant data segments. Data segments were extracted by hand, using Microsoft Word, instead of using computer software (Seale, 2010). This was time-consuming, but helped to develop a more nuanced and richer understanding of the data.

In cross-national interviews a single line may not adequately convey meaning, or sentiment. Therefore, segments of text were coded as they occurred naturally (Bazeley, 2013) to maintain coherence and context (Rapley, 2004). A worked example using an extract of an interview is shown in Appendix 10. Initial coding and data extraction identified some expected, but also some novel themes (Creswell, 2014). Outlying ideas can be useful in recognising variations to the predictable (Thorne, 2008) and maintaining context (Braun and Clarke, 2006) so codes not immediately 'fitting in' were not discarded (Braun and Clarke, 2006). A list of the initial codes is shown in Appendix 11.

### **3.4.5.3 Phase 3: Searching for Themes**

As evidenced in Appendix 11 initial data analysis led to a large number of codes covering an array of issues. There is debate as to what constitutes a theme (Braun and Clarke, 2006), but repeated listening of interview recordings to check their content, meaning and sentiment aided iterative consideration of codes (Thorne, 2008). Such activities facilitated the merging of some codes with others. As suggested by Braun and Clarke (2006) the construction of thematic maps can be useful in linking multiple initial codes into broader overarching themes. Appendix 12, constructed in the earlier stages of this process, shows the development of provisional overarching themes and their subthemes.

#### **3.4.5.4 Phase 4: Reviewing Themes**

The main themes and their subthemes were reviewed, some were merged, and those not relevant to the research question removed. Themes not relevant to the research question included data related to staff whose assisted dying experiences involved a relative (Appendix 12). The perspectives of these accounts differed from those in their role as a member of staff, but could be the subject of future publications. This stage included a review of the original transcripts and memos (Hunt, 2009). This guarded against premature analytical closure (Thorne, 2008) or themes being framed in the context of an expected outcome instead of the real data (Hunt, 2009). It also reaffirmed the purpose of the inquiry (Patton, 2015) and aided confirmation of the initial analytical ideas (Thorne, 2008).

#### **3.4.5.5 Defining and Naming Themes**

Qualitative research data needs to be interpreted, by inductive reasoning (Thorne, 2008), beyond the surface level of patterns and themes (Denzin and Lincoln, 2011). To describe the development of data from surface to a conceptual level Braun and Clarke (2006) differentiate between a '*semantic*' and a '*latent*' approach. A semantic approach focuses on the data at its surface level. This can be useful in identifying patterns, and the broader implications interpreted in the light of previous literature. In this study four main themes have been derived using a semantic approach. Named as *Assessment and its*

*Challenges, Preparing Staff and Learners, Assisting a Death and Bereavement Care and Beyond* these themes are defined in Appendix 13.

Latent analysis, Braun and Clarke (2006) suggests, goes beyond a surface level exploring underlying ideas, assumptions, ideologies and conceptualisations (p.84) that may shape, or form, the semantic content. Such analysis can be applied across a data set, but here it is applied to two subthemes which arose in the data and which, based on the findings of the literature review (Chapter Two), offered an opportunity to gain new insights. Discussed in Chapter Five (5.2) and (5.5.1) these subthemes are 'it's never normal' and the issues related to conscientious objection and support for assisted dying.

### **3.5 Validity, Reliability and Rigor**

The concepts of *reliability* and *validity* arose from the natural sciences (Burr, 2015). In their traditional context *reliability* relates to the replicability of the research findings (Burr, 2015) and *validity* to the accuracy of the conclusions drawn from it (Lewis and Richie 2003). In constructivist research, which is based on a 'snapshot' view of a phenomenon, such concepts have been challenged (Lincoln and Guba 1985; Burr, 2015). This challenge arises because perception and cognition are active processes (Hammersley, 2013) and co-exist with the socio-cultural forces that aid their construction. Therefore,

constructed truths are subjective and will vary across time and place (Berger and Luckmann, 1966). Nonetheless, to be considered credible, qualitative research needs to demonstrate rigor to its approach (Morse, 2015; Burr, 2015).

Systematic analytical procedures (Burr, 2015) and the strength of the data (Lewis and Ritchie, 2003) are suggested as aiding rigor in qualitative inquiry; of which both are evidenced in this study. Schwandt, Lincoln and Guba (2007) make a number of additional recommendations that have also been applied. These include searching for novel themes differing from the most common response to interview questions and not excluding them, spending time in the field, and checking facts and assumptions. Providing in-depth information about methods allows others to assess, not only the accuracy (Burr, 2015), but the congruence between the research question and methodology (Morse, Barrett, Mayan, Olson and Spiers, 2002). Language matters in constructed inquiry (Burr, 2015) therefore, direct quotes are included in the findings (Chapter Four) to permit appraisal of the language of staff and to aid determination of the salience of the themes.

### **3.5.1 Member Checking**

To enhance rigor a 'member-checking' (Lincoln and Guba, 1985) exercise took place at an Open Invitation Research Summary [OIRS] to review the provisional

findings. This required an amendment to earlier ethical approval and consent procedures which are discussed in Ethics (3.6).

All staff from both research sites, including interviewed staff, were invited to attend. Since my previous visit, the chronic disease care centre (site A) had been reorganised with staff split between two sites, a process that was ongoing. It was a challenging time for staff. Therefore, for practical reasons, it was decided to hold the event at the new site where a suitable room was available and more staff were likely to be able to attend. An internal email was sent to all staff specifying the date and time of the event. Staff previously interviewed also received a separate invitation sent to the email address they volunteered at interview. These Invitations included the option of receiving information by email to preserve anonymity if they did not want to attend in person, but no-one took up this option. The Participant Information Sheets for all staff invited to the Open Invitation Research Summary are in Appendix 14.

There is some debate on whether or not such validation exercises are helpful (Miles and Huberman, 1994; Seale, 1999), but it allowed a small group of staff, comprising of one doctor and three nurses, all previous participants, to view a PowerPoint presentation and add extra information. No offer to withdraw information derived from interviews was made. The session was audio-

recorded and transcribed with a transcript segment shown in Appendix 15. The information gained from the Open Invitation Research Summary is included in Chapter Four (4.4.5), and discussed in Chapter Five (5.2).

### **3.6 Ethics**

To ensure participation causes no harm (Gray, 2014) all research participants' rights and interests are protected by international codes based on the Declaration of Helsinki (World Medical Association, 2010), national and local codes, and guidelines from professional bodies (Royal College of Nursing, 2011). Ethical approval from Lancaster University Research Ethics Committee was granted in January 2013 [FHMREC12017] (Appendix 16). As the research involved only staff, full ethical approval in the Netherlands was not required (Central Committee on Research Involving Human Subjects, 2017), but because of topic sensitivity a research proposal was submitted to Maastricht University Executive Committee, with permission to proceed granted in August 2012 [METC 12-5-043] (Appendix 16). In addition approval was sought and received from the Boards of the participating organisations (Gray, 2014).

Lancaster University Research Ethics Committee granted an Amendment in March 2015 [FHMREC14048] (Appendix 16) for the Open Invitation Research

Summary. Amendment information was also sent to, and acknowledged by, Maastricht University Executive Committee.

### **3.6.1 Informed Consent**

All participants were given at least 24 hours to read and understand (Bryman, 2016) a Participant Information Sheet (Appendices 7 and 14) prior to the interview and Open Invitation Research Summary. Participants were asked if they had any questions related to the study prior to their interview and the Open Invitation Research Summary. Consent Forms (Appendix 17) were read with the participant/s to ensure there was clarity in the purpose of the interview and Open Invitation Research Summary (Gray, 2014). All consent forms were signed prior to the start of any audio-recording. Participants were informed of their right to withdraw material (Stark and Hedgecoe, 2013) up to two weeks post-recording, although no-one took up this option.

### **3.6.2 Confidentiality and Anonymity**

Participants were assured of anonymity (Stark and Hedgecoe, 2013). Rooms for the Interviews and the Open Invitation Research Summary were sited away from clinical areas so that staff members were not easily seen arriving or leaving, aiding local anonymity (Stark and Hedgecoe, 2013). In data analysis

participants were allocated to a professional group rather than being identified by their disciplines which, for some therapists, may have heightened the risk of identification. A breach of confidentiality however, is permitted if harm is likely to the participant or others (Bryman, 2016). Therefore, procedures were in place should a participant divulge any illegal activity. Participants were warned of this at the start of the interview but, in the event, no illegal actions were divulged.

Procedures to uphold the United Kingdom's Data Protection Act (Data Protection Act, 2005) have included anonymising and using pseudonyms in transcripts, keeping consent forms and transcripts in a locked cabinet and participants' personal details separately on encrypted, password protected mobile devices. Deleting all non-encrypted recorded data, not sharing information about participants, nor identifying the organisation or city where the study took place has also been necessary (Ryen, 2004). In qualitative research the use of quotes may also inadvertently identify participants (Bryman, 2016) particularly if the numbers of participants with a specific view, such as conscientious objection, is small. Therefore, anonymity procedures will also be applied to future publications, with participants contacted if there is a risk of them being identified.

### **3.6.3 Psychological Well-Being**

End-of-life care and assisted dying are sensitive topics with staff vulnerability a concern and, as in all research consideration of their well-being was needed (Miles and Huberman, 1994). Occasionally, if participants' experiences included personal accounts involving a patient or relative of theirs, some emotions were evident. When this occurred an offer was made to stop the interview, but this was always refused. Participants' well-being was also checked before they left the interview room and the local source of psychological support was included at the end of the Participant Information Sheets (Appendices 7 and 14)

### **3.7 Summary of Chapter**

This chapter gives an overview of research paradigms and their philosophical origins to position the constructivist approach taken in this study. Terminology and the tenets of constructivist inquiry are outlined. Constructivist inquiry seeks a contextualised understanding of phenomena and requires iterative methodology and inductive reasoning. The origins and characteristics of qualitative research are explored including its use in end-of-life care research and the rationale for its use in this study. The qualitative methods used in this research are outlined including sampling and recruitment, data collection, the challenges of conducting cross-national interviews, and data analysis. The procedures undertaken to promote reliability, validity and rigor are outlined

which included member checking. The ethical principles and procedures considered prior to, during, and in the dissemination phase of the study conclude the chapter.

## **Chapter Four: Research Findings**

### **4.1 Introduction**

This chapter reports the study's findings after the application of the analytical phases advocated by Braun and Clarke (2006). This chapter corresponds with Phase Five 'Defining and Naming Themes' (Braun and Clarke, 2006) where the themes developed from the semi-structured interviews with staff are identified and presented. Biographies, using Dutch names as pseudonyms, have been added (Appendix 8) to remind the reader of the professional role and characteristics of the participants. Quotes are attributed to staff members using these pseudonyms with the research site identified by an 'H' for hospice or the abbreviation 'CDCC' for the chronic disease care centre.

### **4.2 Defining and Naming Themes**

Multiple interpretations of qualitative data are possible (Burr, 2015), but amalgamation and analysis (Braun and Clarke, 2006) of the interview transcripts from the two study sites, has generated four broad semantic themes focusing on the description of staff experiences along a trajectory from an initial assisted dying request to bereavement care and beyond.

The themes are:

- i) *Assessment and its Challenges*
- ii) *Preparing Staff and Learners*
- iii) *Assisting a Death*
- iv) *Bereavement Care and Beyond*

These broad themes contain a number of subthemes to give structure and add detail (Braun and Clarke, 2006). Themes and subthemes are shown in Table 10.

**Table 10: Themes and Subthemes**

<b>Theme</b>	<b>Subthemes</b>
<b>Assessment and Its Challenges</b>	Workload Issues: Frequency of Requests Exploration and Negotiation Perceptions of Patients' Personal Characteristics Demanding Patients and Families 'First palliative care' Conscientious Objection Meeting Legal Requirements Refused Requests 'Changing borders and minds' Psychological Status Assessing and Supporting Families The End of Life Clinic
<b>Preparing Staff and Learners</b>	Staff Preparation: 'Averij' Use of Supportive Networks 'Is everyone comfortable?'
<b>Assisting a Death</b>	Meeting Final Requests Managing the Death Saying Goodbyes and Life's End Lethal Medication 'It's never normal' The Use of Humour
<b>Bereavement Care and Beyond</b>	After-death Procedures Legal or Not?: 'Waiting for the all clear' Emotional Experience for Staff and Coping Strategies Bereavement Care : 'Doing a bit extra' Families and Grieving 'Never forgetting'

## 4.3 Assessment and Its Challenges

### 4.3.1 Workload Issues: Frequency of Requests

Assisted dying was permitted at the hospice in this study, but the frequency of requests created a considerable amount of additional work for staff. This was discussed by Gwen, a nurse manager, who had fifteen years of experience at the hospice:

*“I think fifty percent of the people who are coming to the hospice have the wish to discuss euthanasia.” (Gwen: H)*

Often hospice patients arrived with completed advance directive forms specifying an assisted death in the mistaken belief this was sufficient to ensure an assisted death would occur. This illustrates a lack of public awareness of the Dutch legislation and the essential legal criteria that need to be met such as lasting and unbearable suffering. Despite the challenges it posed, the hospice staff interviewed, predominately nurses with considerable experience (Appendix 8), did not identify the increased workload as a problem. For hospice doctor Cornelia however, who conscientiously objected to assisted dying, it was a cause of considerable frustration as discussed later in this chapter (4.3.6).

Such a large volume of requests however, were not necessarily experienced across clinical specialties and at the chronic disease care centre, respiratory doctors Liam and Ruben, cited low numbers of assisted dying requests. This may suggest that the clinical and existential triggers for assisted dying are not common across all patient groups. Doctor Liam linked assisted dying to the challenges he faced when talking about essential care issues such as resuscitation or mechanical ventilation:

*“A minority of patients ask for euthanasia. There are issues that are really important, for example ‘do not resuscitate’ and mechanical ventilation, but when you discuss the future some patients block discussion. They don’t want to think about it.” (Liam: CDCC)*

In contrast, doctors with primary care and haematology experience cited high volumes of requests. Relatively high request numbers in primary care are not surprising as the majority of Dutch assisted deaths occur at home. In haematology the reasons were less clear, but staff suggested poor prognosis, patient isolation, and aggressive treatments as contributory factors.

At the hospice and chronic disease care centre staff highlighted the influence of age on requests with Lara (doctor), Eva (nurse) and Tess (therapist) all suggesting ‘older’ patients were less likely to initiate assisted dying requests. Defining ‘older’ is problematic, but Eva defined it as patients in their eighth

decade and older. This issue was taken further by therapist Noah a 'lapsed' Catholic working with the elderly, who suggested that religious beliefs may limit requests for assisted dying in this patient group. Statements from Noah and from other therapists also highlighted that patients directed their requests to therapists as well as doctors and nurses.

### **4.3.2 Exploration and Negotiation**

At both research sites all staff groups 'talked through' assisted dying requests which when explored, related to a fear of future symptoms, or to the dying process. Although patients often lacked knowledge of the necessary legal steps, a request promoted open discussion of dying including palliative care options.

Nurses viewed some patients as considering it "*too easily*" (Zoe: CDCC), without being aware of or considering other options, such as palliative care, so assessing seriousness was important. Nurses at the hospice and at the chronic disease care centre described a number of strategies to explore seriousness. For some nurses it was also personally important for them to understand the patient's reasoning. If they did not, this might impede the progress of a request. Hospice nurse manager Gwen explained her strategy:

*“You have to look very clearly. What’s the question? What is the question behind the question?” (Gwen: H)*

This strategy allowed Gwen to identify concerns amenable to an explanation about dying or to affirm the value of palliative care. This initial exploration of an expressed interest in an assisted death was used by nurses at both research sites, suggesting the approach has utility. Doctors’ consideration of initial requests however, differed and they looked for clarity in the patients meaning, as Doctor Ilse explained:

*“Sometimes patients ask for euthanasia, but they mean they want a ‘Do Not Resuscitate’ [DNR] order and they do not understand the terms. Real requests are quite scarce.” (Ilse: CDCC)*

Doctors also screened more specifically for clinical issues which might have led to the request, such as unresolved pain or evidence of depression, and looked for consistency in the patient’s reasoning.

Sometimes the screening of an initial request, particularly by nurses, focused on the patient being encouraged to ‘try’ a natural death and, after an explanation of symptom control measures possible, this resolved the patient’s request. Being able to discuss assisted dying openly, alongside other options such as palliative care, was welcomed by staff as senior nurse Zoe explained:

*“I think it is good that they are allowed to talk about it... they have to die and they are thinking about ways of dying to keep it as humane as possible.” (Zoe: CDCC)*

Patients however, varied in their openness to dialogue with some being more open than others. It was acknowledged that assisted dying requests also served as an ‘insurance policy’ against the suffering patients feared might arise in the future. In these cases the possibility of assisted dying gave patients an added a sense of security, although there was no guarantee that their request would be granted.

Therapists’ views on assisted dying were canvased by patients during exercises for mobility and for breathlessness and they described some of their exploratory tactics, as therapist Noah explained:

*“...you have to be careful and spend time. He is not asking for a stick or a mobiliser.” (Noah: CDCC)*

Instead of focusing on clinical issues some therapists explored the patient’s quality of life, using a brainstorming approach, to assess hopelessness. After exploration therapists, like nursing staff, would refer a serious request to a doctor for further discussion and assessment. This suggests that, in care environments with a multidisciplinary team, assisted dying requests may be

screened by a range of staff before a formal review by a doctor. This might not have occurred at the hospice as it had less staff in fewer disciplines.

### **4.3.3 Perceptions of Patients' Characteristics**

Staff suggested patients with persistent requests for an assisted death often had severe refractory symptoms resistant to effective palliation. However, staff also highlighted patients with equally severe symptoms who did not request it identifying other personal characteristics as important. Doctor Ilse described assisted dying patients as typically:

*"...patients for whom autonomy is very important, who struggle with care dependency, who cannot accept it ...and who want to organise their own death."* (Ilse: CDCC)

This suggests pain, discomfort and symptom burden may not be the prime motivation for an assisted death, with staff identifying other motivators.

Doctor Cornelia suggested:

*"They have got birth control, financial control and now they want death control."* (Cornelia: H)

In this quote Cornelia linked the patient's desire to maintain control of death to modern lifestyles which, as a conscientious objector, she resented. Staff however, also identified patients who had gone to considerable lengths to

achieve an assisted death, demonstrating that high levels of determination were also needed. Nurse Zoe cited a case involving the transfer of a dying patient from a religiously sponsored hospice, which did not permit assisted dying on its premises, to an acute hospital to die. Zoe knew the patient well describing the patient's action as:

*"...typical, because she wants to decide what to do herself." (Zoe: CDCC)*

Other staff such as nurse Gwen (H) and doctor Lara (CDCC) recounted that patients granted an assisted death tended to be well-educated and articulate, suggesting this was a necessity as patients needed to convince doctors of the validity of their request.

#### **4.3.4 Demanding Patients and Families**

Late requests sometimes arose from the distress of families seeing their relative in a comatose state. As hospice doctor Cornelia explained:

*"...some patients can be really, really demanding and even the family. I've had patients who are semi-comatose and the family demand euthanasia because they can't stand watching Mother and they don't understand that you can't just kill the patient." (Cornelia: H)*

Although understandable, such actions would be illegal as, by definition, a Dutch assisted death has to be voluntarily requested by the patient. Doctors

were not alone however, in experiencing requests which frustrated them as hospice nurse Maud explains:

*“She was very ‘I want this’ and I want that’... she was so sick and she had euthanasia on Monday and if she didn’t do it on the Monday I think she would have died on the Tuesday. It was the nurses assessing the patient in front of the doctor ‘Are you sure? ‘Yes, I’m sure I want it now. I thought ‘yes’, but why?’” (Maud: H)*

This quote suggests that hospice nurses may not have been involved in the decision-making process nevertheless; they experienced similar demands from patients as the doctors.

#### **4.3.5 ‘First palliative care’**

Formal assessment of an assisted dying request, particularly for doctors, required examination of a request alongside the legal ‘due care’ criteria. Considering the validity of a request was challenging and neither quick nor easy. Doctors used palliative care as a means of determining if a patient’s suffering was ‘unbearable’, a key legal criterion, notoriously difficult to assess, as Doctor Ilse explained:

*“The first challenge is to optimise my palliative care for these patients...you ask yourself again ‘did I do everything I could to make this suffering bearable’.” (Ilse: CDCC)*

Unsurprisingly Cornelia, a hospice doctor who objected to assisted dying, offered patients specific strategies to alleviate symptoms, such as breathlessness or nausea, and the opportunity to resolve existential issues by talking them through. There was also an acknowledgement that palliative care knowledge had increased over time as Anouk, an experienced nurse educator, stressed:

*“..you see more doctors and nurses aware of the existence of palliative care and more and more and are asking ‘What is better? To continue treatment or move to palliative care? There is, in the last ten or twenty years, a choice.” (Anouk: CDCC)*

There were however, some regrets as Cornelia explained:

*“I think we made the mistake of putting euthanasia in first place and after that we develop palliative care” (Cornelia: H)*

As a palliative care doctor, for Cornelia, the development of Dutch palliative care after the implementation of assisted dying was a frustration.

Notably, nurses and therapists, as well as doctors, were very adept at promoting the value of palliative care and utilising its principles. Vigour in advocating the use of palliative care was not limited to the hospice, but expressed as a primary aim by staff at both research sites. Open dialogue with patients heightened after an assisted dying request, with discussion of fears of dying, the dying process and palliative alternatives to address symptom problems. Noah, a therapist explained:

*“When you are willing to talk about it [assisted dying] you are willing to talk about the whole palliative care procedures.”* (Noah: H)

Nurses also encouraged patients to consider treatment strategies for shortness of breath and feeling sick, but some staff reported that even “*best palliative care*”(Liam: CDCC) did not always relieve all symptoms. Good palliative care however, was cited as paramount when an assisted dying request was unrealistic and attempting to meet the legislative requirements would take longer than a natural death.

#### **4.3.6 Conscientious Objection**

A moral objection to assisted dying permits withdrawal, for any Dutch staff, from cases although the majority (17) in this study, at least initially, expressed being willing to participate. Of the doctors, six expressed being in favour of assisted dying legislation with only one expressing an objection. However, as

evidenced in the staff biographies (Appendix 8), there were grades of support with some staff appearing to doubt that an assisted death was always the best option for patients especially if the patient did not have incurable physical illness. The need to assess each case objectively, and on its own merits, was discussed.

Some nursing staff also appeared 'uncomfortable' during interviews and may have been reluctant to 'speak out' against it. One nurse however, at the chronic disease care centre, did speak out suggesting older nursing 'colleagues' found it "*a little difficult*" (Eva: CDCC) when an assisted death took place. Rather than ethical issues, for some nurses, their participation was influenced by the care taken by doctors during the assessment process and at the end-of-life. Several nurses at the chronic disease care centre named a doctor whose level of care and concern for the patient and staff increased their willingness to participate. Nurse Zoe explained:

*"She wouldn't do it just for fun, not at all. She was not going to do it overnight."* (Zoe: CDCC)

This suggests that, for staff with no moral objection, being included in the decision-making, or seeing requests carefully assessed, may determine whether or not they object to its practice. Both nurses and therapists linked their participation to the assessment time taken by doctors with longer

assessment periods appearing to comfort staff. Some nurses, such as Nurse Zoe, stated that if decision-making was too swift nurses might consider withdrawing their support for a case. Doctors also considered time, but in a different context. Doctor Liam suggested that adequate consideration of requests was not achievable in some clinical environments, such as busy outpatient clinics. He suggested that, in such environments, dialogue about assisted dying was avoided as the ten minute appointments precluded any in-depth discussion. As a practical measure patients making such a request were referred back to their family doctor.

Practice guidance suggests doctors who object to assisted deaths should refer patients to a colleague willing to consider the request, but it was suggested this does not always happen. Patients' requests, Doctor Liam (CCDC) suggested, may be "*blocked*". For conscientious objectors, such as hospice doctor Cornelia, large volumes of requests were onerous. Despite objecting she had to conduct initial evaluations to determine seriousness, before deciding whether or not they warranted referral to the patient's family doctor who could proceed with formal assessment. She explained her thoughts:

*"I can understand it for some people, who are really suffering and you can't manage to take all the pain away. I can totally understand this patient wants euthanasia, but that does not mean that I want to do it."*

(Cornelia: H)

During the interview she was animated and angry, seeing assisting dying as an unwelcome extension to her role. She identified time periods, such as before a holiday, when dealing with frequent requests had become an emotional burden. She also suggested high volumes of requests contributed to an increased turnover of hospice medical staff, but this was impossible to verify. Other staff such as nurse Famke however, felt it was too easy for nursing colleagues to specify an objection to assisted dying and used this to avoid engaging with the assessment process. This, Famke suggested, negated the positive influence a nursing contribution could make to the decision-making process.

At the chronic disease care centre (site A) people with dementia could live on-site in small homes designed for three to six people and several staff raised the issue of assisted dying for this client group. A television documentary shown at the time of the interviews might have raised awareness. Although potentially legal in early stages of the disease and, with an advanced directive in its later stages, some doctors refused to assess such patients on the grounds that adequate appraisal was impossible. As Doctor Ilse explained:

*“The law does allow us to perform euthanasia with dementia. For me it is really a step too far because, when a patient cannot make a voluntary request because of cognitive disorders, I really cannot perform euthanasia.” (Ilse: CDCC)*

Other staff recognised this dilemma, citing dementia patients who prior to advanced disease had requested euthanasia only to appear to “*live happily with their dementia*” (Abe: H), whilst others in advanced disease appeared to be extremely distressed with a poor quality of life. Some staff felt the current situation was ‘unfair’ for this client group, with staff from all professional groups suggesting more discussion was warranted alongside an urgent need for more professional guidance for healthcare staff.

#### **4.3.7 Meeting Legal Requirements**

Unfamiliarity with legal procedures caused some doctors concern and occurred because assisted dying cases are relatively rare in clinical practice. Doctors sought legal and procedural advice, and a second medical opinion, most often from the ‘Support and Consultation for Euthanasia in the Netherlands’ service colloquially called the ‘SCEN’ (pronounced ‘scan’), doctors. Doctors in training posts also took advice from their supervisors. Seeking a second medical opinion was seen by some doctors as daunting or ‘delicate’ as medical opinions can vary. Nonetheless, despite their concerns, independent assessment was valued as respiratory doctor Liam explained:

*“It is very important to have the opinions of others... an independent doctor who can see from a distance. How can I [as the patient’s attending doctor] judge if euthanasia is the right option in this case?”* (Liam: CDCC)

Beyond an independent medical opinion, Dutch doctors do not need to confer with other members of staff, but at the chronic disease care centre, a multidisciplinary meeting to discuss a serious request was valued by all staff groups. As Doctor Ilse explained:

*“I think when there are conflicts on the unit that would make it almost impossible.” (Ilse: CDCC)*

This suggests that despite their supremacy in the eyes of the law, for some doctors, the agreement of staff from other disciplines was essential for a request to proceed.

#### **4.3.8 Refused Requests**

As well as consulting with others, doctors screened requests for any signs of coercion and, sometimes, an assisted death was refused because doctors doubted the patient’s voluntarism. Precisely defining the reasons for their discomfort was difficult, but it could apply to actions such as giving away money or possessions, which were viewed as potential evidence of coercion. Refusal on these grounds did cause disappointment, as Doctor Ilse identified:

*“She [the patient] was disappointed at first [by the refusal], but a few months later she was doing really well, enjoying life and said ‘I’m so happy you did not do it’.” (Ilse: CDCC)*

This suggests patients do not always accurately predict their future physical and psychological status and ultimately some patients were grateful for a request refusal.

#### **4.3.9 'Changing borders and minds'**

Legally doctors have the primary role in assessment of a Dutch assisted death and they alone can authorise it, but nurses cited dialogue with patients which sometimes influenced outcomes. Abe, a hospice nurse with mental health registration and neurological experience, highlighted that patients with long-term incurable diseases could have several mind changes about the timing of their assisted death. This phenomenon may not be widely recognised. In a long account of the care given to a patient with Huntington's Disease, who also periodically threatened suicide if his request for an assisted death was refused, Abe described the patient 'changing his borders' on several occasions:

*".. he can't eat anymore [the patient] and he said 'the border is when I can't eat my food anymore'...then I want to euthanasia'. Then he came to the border, 'No, I try a tube' and his border changed. And then there came a moment he can't walk anymore. 'You can try with a wheelchair and just try' and the border changed."* (Abe: H)

Ultimately however, this did not alter the patient's desire for an assisted death despite initiatives to relieve symptoms and the resolution of practical issues.

When the patient considered himself 'no Father anymore' to his children he requested an assisted death and died by lethal injection with Abe present. This suggests that, for some patients with degenerative incurable disease, assisted dying may be a dynamic 'companion' to care, with on-going dialogue and reevaluation about its potential merits over care with staff.

As noted earlier some assisted dying requests are refused by doctors. Less commonly cited were cases assessed as suitable, but after dialogue with other staff, the patient chose not to pursue it. In a case involving a patient with a painful neuropathy, Abe was instrumental in gaining a referral to a pain specialist and encouraged the patient to rethink her options, as he explained:

*"She wanted to have euthanasia because she had a lot of pain and two doctors agreed and she asked me 'What should I do?' I can't take the pain anymore but should I stay for my kids? 'I said 'It's your life, you must make the decision, but if you can, you want to stay alive for your kids'."*

(Abe: H)

Abe stayed in contact and, after a successful nerve block and becoming a Grandmother, the patient was grateful for her decision not to die, although the prospect of assisted dying as a future option was still of comfort to her. Such cases highlight the potentially significant influence of nurses despite a lack of recognition in Dutch law and research.

#### 4.3.10 Psychological Status

Dutch legislation requires a determination of psychological status which can be challenging, although psychiatric illness is not necessarily a barrier to achieving an assisted death. For doctors at the chronic disease care centre (site A), this included referral to an on-site psychologist with an additional psychiatric referral if mental capacity was in doubt. Doctor Ilse explains this process:

*“I explain to the patient I have to be sure about their seriousness and often the psychologist is already involved with these patients, but if not they will be seen by a psychologist and, if there is any doubt, they will be also be seen by a psychiatrist, to assess this issue.” (Ilse: CDCC)*

Referral to a psychologist was not mentioned at the hospice and might not have been available. Staff however, at both research sites, recognised the potential of depression manifesting itself in patients due to their advanced disease. Nurses particularly recognised that a patient’s desire for an assisted death could fluctuate with ‘bad’ and ‘good’ days influencing their decision-making. Nurse Emma highlighted this phenomenon:

*“.....it’s often like ‘today it’s a bad day and maybe it’s going to get better’. And when they have the chance for rehabilitation they are more positive and they are going to ‘have sweets sometimes’ [some good days].”*  
(Emma: CDCC)

Nurses also noted other alterations in psychological status, such as a dramatic uplift in mood of a cystic fibrosis patient after his euthanasia request was granted following an assessment process that took several months. Nurse Emma had cared for the patient on several admissions describing him as always *“fighting, fighting, fighting”* (Emma: CDCC) whilst he awaited a lung transplant. She was shocked by his request to die which was granted whilst she was on holiday. On her return to the ward she described his mind state as:

*“He was another person, relaxed, a happy person and it was good.”*

(Emma: CDCC)

The reasons for this apparent mood improvement are unknown, but the granting of his request after several months of assessment from the multi-disciplinary team, may have been seen as a welcome release from psychological and physical discomfort.

#### **4.3.11 Assessing and Supporting Families**

Staff discussed the challenges of assessment which, if there was no conflict within the family, could be a rewarding experience. When conflict did occur however, it could be difficult to manage and added significantly to the challenges for staff. Jade, a social worker, assessed families' abilities to cope with and to support the patient's assisted dying request. Typically she met with family members several times to help them with a range of emotions that

could be conflicted:

*“They may have the feeling they are not important enough to stay alive for. They have to deal with it and it is difficult. They say, 'He needs help and I can't give him the help. I have failed'. Or 'I don't want to be selfish' [wishing the patient would stay alive]. Those feelings come and go’.”*

(Jade: CDCC).

Social workers also prepared children, if old enough, to understand a death was expected. At the hospice however, where a social worker may not have been available, nurses stepped into this role, although some families prepared children themselves. During assessment staff developed close relationships with patients and their families which could be emotionally demanding, but were also cited as learning experiences. Emma, a relatively young nurse, describes a couple’s reaction to the husband’s imminent assisted death:

*“It was beautiful to see how man and wife communicate with each other and it was unbelievable.”* (Emma: CDCC)

The quality of communication this couple exhibited surprised Emma who described it as a valuable experience. To support the family she was also able to assist the patient to make a will and organised nice meals for the couple on the ward prior to the patient’s death.

#### 4.3.12 The End of Life Clinic

Only the hospice nurse manager Gwen had direct experience of the clinic, having been consulted in respect of a resident in a nursing home adjacent to the hospice, but she expressed doubt about openly discussing the case in detail. At the time of my visit the clinic had been the topic of a film documentary and several staff discussed it. The majority of staff interviewed disagreed with its inception, or had other concerns, as Doctor Ilse explained:

*“I have problems [with the clinic] because euthanasia is something that is part of a treatment trajectory you go through together as a patient and the physician. It feels wrong if patients can go to a clinic getting their euthanasia as a sort of product and it should not be like that.”* (Ilse: CDCC).

Valuing care continuity, particularly during the assessment process, staff were concerned that a lack of a longstanding relationship with a patient and their family may render patients vulnerable. Some questioned the competence of the clinic’s staff, although at the time of the interviews the clinic’s website suggested nursing staff should have ten years of clinical experience before applying for advertised positions. Staff did not suggest the clinic was acting unlawfully, but some felt it was “*searching the boundaries*” (Tim, CDCC) of the law, potentially exposing patients to risk. Doctor Liam however, was more circumspect. In support of the clinic’s procedures he suggested that their staff may have more time to assess patients than staff in busy acute hospitals:

*“...they say, ‘We have at least four conversations of one hour’. They say they know the patient better than the patient’s General Physician [GP]. If they work very carefully, take their time with, at least four consultations, they can come to a right decision, a reasonable judgement.” (Liam: CDCC)*

Other doctors such as Lara (CDCC) also suggested the clinic’s portrayal in the media might not be accurate as some requests were declined. On occasions she suggested it had also supported inexperienced doctors to deliver lethal medication, a difficulty identified later in 4.5.4.

#### **4.3.13 Summary ‘Assessment and Its Challenges’**

Staff from all professional groups received and explored assisted dying requests. Being able to understand the patient’s reasoning was important to staff, but often requests were resolved by discussing fears about dying and palliation. Requests were frequent at the hospice although only staff who conscientiously objected found it burdensome. High request levels were suggested in haematology. Assisted dying patients were articulate, but also had to be determined and persistent. Patients who demanded an assisted death however, caused consternation for staff particularly if their reasoning was unclear. Some requests were refused for which some patients were perceived as grateful.

Palliative care was uppermost in the minds of staff and it aided doctors in determining if the patient's suffering was 'unbearable'. Objection to assisted dying by doctors could be firm, but was also directed towards specific patient groups such as those with dementia. For nurses, however, it was a more fluid concept sometimes related to the care taken by medical staff. Assessment of the patient's psychological status was a challenging area for staff, with recognition of mood fluctuations in advanced illness. Interventions by nurses could delay assisted deaths, but sometimes also altered the patient's mind-set. If available, a social worker aided the support of families which could also include the preparation of children. Staff from all professional groups expressed concerns about the End of Life Clinic, but not all staff agreed that its procedures negated an adequate assessment of requests for an assisted death.

#### **4.4 Preparing Staff and Learners**

##### **4.4.1 Staff Preparation: 'Averij'**

The hospice staff interviewed had many years of experience, typically being qualified for at least fifteen years as illustrated in the staff biographies (Appendix 8). In response to the question of staff preparation for assisted dying legislation, hospice nurse manager Gwen suggested that their care experience, and fifteen years of permissive laws, prepared her staff adequately for their responsibilities. Other staff initially agreed that no extra preparation in the

form of education, end-of-life care training or psychological support was necessary, with Nurse Abe explaining:

*“... my partner is also working in a hospital and I have a lot of friends and I talk about it but, no, I don't need any special help.” (Abe: H)*

There were however, inconsistencies. Later in his interview Abe highlighted the value of his many years of nursing and life experience in dealing with assisted dying patients using the Dutch word 'averij' (pronounced *a-ver-lay*) and meaning the ability to 'sustain heavy damage', to explain his thoughts:

*“You can prepare for it but the most of what you have to have is life experience 'averij'. I have seen in life what illness can do to people. You can be sick for long years and, now and then, when someone says 'No, it is enough'. It is enough.” (Abe: H)*

Younger nursing staff with less experience, although keen to care for such patients, had been shocked by the emotional demands such cases placed upon them. Famke (CDCC), a young nurse, talked at length about her first case of an assisted death which did not go 'smoothly'. The request from the patient, who was well-known on the respiratory unit, was a surprise, but it led to new and unrecognised responsibilities for her as she explained:

*“It was my first case and she 'claimed' me a lot. She wants to talk a lot and she wants me to have conversations with her, with her children, with her Mother, her sister and a few of her friends and that was difficult. And*

*she asks if I want to be by her side at the euthanasia.” (Famke: CDCC)*

This case was complicated by conflict within the family which ultimately led to distressing scenes at the time of the death. Although initially flattered by the patient’s trust in her, the situation was demanding for Famke, but she did not identify any preparation that might have helped. During her interview however, she identified strategies discussed later (4.5.2) to better manage an assisted death next time it arose.

Other staff groups, such as the therapists, were often less involved with assisted dying patients and did not suggest any special preparation for their role. As a retired nurse and nurse educator Anouk however, raised the issue of learner preparation, having used reflective exercises with nursing students to give them a sense of ‘where they stood’ in the process. Warning against ignoring the preparation of learners who may experience similar feelings, but may not have access to the same level of support as qualified staff, she stressed the importance of getting a balance between knowledge and feelings to aid resilience.

#### 4.4.2 Use of Supportive Networks

For doctors the Royal Dutch Medical Association's Support and Consultation service was acknowledged as an important source of support. As well as providing independent consulting doctors, this service was valued for emotional support during the decision-making and at later stages of an assisted death. Doctor Ilse explained its scope:

*"We do have physicians educated about euthanasia and they are not only for seeing whether or not you are acting according to the law but also they have a counselling service."* (Ilse: CDCC)

However, medical staff who objected to assisted dying had not considered accessing such counselling services despite acknowledging that receiving and assessing assisted dying requests was stressful. So, although the Dutch Medical Association's support service was seen as a valuable for doctors willing to perform assisted deaths, it appeared to be considered inaccessible by doctors who did not.

Nurses obtained professional guidance from the Comprehensive Cancer Centre, a Dutch national organisation with regional offices, which promotes oncology and palliative care. The Centre provides advice on dealing with requests, the decision-making process, implementing an assisted death and care of the body after death. Some nurses had also received local training on their assisted dying role and had sought out information from the Internet, or

read professional articles and case studies. Zoe (CDCC), an experienced nurse, encouraged other nurses to learn about it, especially the legal boundaries of nursing actions. She explained:

*“Know what the doctors may ask you and what they can't ask you. I've heard sometimes [at other sites] they let nurses do more than they are allowed to do. You have to know your rights. You're not a doctor” (Zoe: CDCC)*

This advice would appear to be useful as Dutch nurses are not allowed to handle lethal drugs and the illegality of such actions was stressed by the nurses at the chronic disease care centre. At the hospice (site B) however, less emphasis was placed on this issue with nurse manager Gwen expecting nurses to be present at the bedside. This is not required in law and, beyond ‘supporting the doctor’ the reason for their presence was not specified.

#### **4.4.3 ‘Is everyone comfortable?’**

Prior to an assisted death at the chronic disease care centre (site A), a multidisciplinary team meeting took place, including therapists, to check staff were ‘comfortable’ with the final decision. For some doctors staff agreement was seen as essential, but nurses and therapists also valued these meetings, as therapist Jade (CDCC) explained:

*“...when you talk about it the decision [the final decision] you do it with the team and with the doctor responsible for it.” (Jade: CDCC)*

At the hospice however, the range of disciplines available was not as extensive as at the chronic disease care centre and multidisciplinary team meetings to discuss the case prior to the act were not held. Nevertheless, the hospice nurses talked about assisted deaths amongst themselves. Nurse Maud explained:

*“We talk a lot about what’s going to happen or happened” (Maud: H)*

This does however, suggest that decision-making at the hospice was not a collaborative exercise and nurses (Maud: H) recounted assisted deaths with which they were not comfortable, despite the patients being insistent that an assisted death was their preferred option.

#### **4.4.4 Summary: Preparing Staff and Learners**

Doctors valued their professional support service, but this was not available to nurses or therapists. It was also not considered accessible by conscientious objectors. Nurses highlighted the value of professional and life experience in coping with the rigors of assisted dying in clinical practice. The need for the preparation of learners was also highlighted. All staff groups found multidisciplinary meetings, to review decision-making and determine if staff

were 'comfortable' with the final decision, as useful emotional preparation for an assisted death.

## **4.5 Assisting a Death**

### **4.5.1 Meeting Final Requests**

Staff caring for assisted dying patients participated in a range of final requests including making keepsakes, ordering special meals and facilitating a final cigarette. Sometimes patients merely requested 'normality' in their routine on their final day. Occasionally their desires were more elaborate and staff went to extraordinary lengths to meet final requests. In one example hospice nurse Abe visited Amsterdam with a patient to revisit significant places from the patient's youth. Visiting his childhood home, school and favourite beach they also filmed a video for the patient's young children. Chosen because of his familiarity with the city and his status as the patient's 'favourite' nurse, during the visit Abe was able to hear the patient's life story and the impact of illness, which he recalled as a valuable learning experience.

Other staff cited similar events such as a doctor ordering a final meal for a patient, but such activities were not limited to doctors and nurses. Hospice therapists undertook many activities including beauty treatments, aromatherapy, making cakes for visitors and, in one case, writing bereavement cards with the patient to be sent after her death. Sometimes these culminated

in a final day event such as the one described by hospice therapist Tess for a patient paralysed by motor neurone disease:

*“She asked me to make a good day of that day. I have to arrange everything and in the evening she had euthanasia. It was very nice weather. It was in May and for the whole day she invited people to be there: her brother, sister, father, mother and her boyfriend, her two children, me and her sister. The final day was very nice. I do her hands [a manicure], a massage, and a foot massage. I make cakes and it was a beautiful day.” (Tess: H)*

Such elaborate final activities were not mentioned by staff at the chronic disease care centre perhaps because it was a busier facility. However, Fay (CDCC) the centre’s creative therapist, supervised art work, such as making keepsakes, but she found it difficult to judge how much patients wanted to talk about their decision. Nonetheless she saw such opportunities as ‘special’, memorable and a rewarding experience.

#### **4.5.2. Managing the Death**

The workload of nurses was reduced on the day of an assisted death suggesting recognition of its potential to be stressful by managers and institutions. At the chronic disease care centre nurses worked on a one-to-one basis with the patient, being relieved of all other responsibilities, with their manager

instructing them:

*“We don’t need you to do other work today; you will just look after him’.”* (Emma: CDCC)

At both sites additional staff or volunteers were rostered to provide extra support to staff. At the chronic disease care centre (site A) immediately after the death staff heavily involved in caring for the patient were allowed to go home. Other staff, including therapists who had known the patient, visited the ward to have a coffee, to talk through the experience and to support their colleagues. At the hospice (site B) the nurse manager Gwen had tea with the attending doctor which she considered an important supportive measure.

### **4.5.3 Saying Goodbyes and Life’s End**

Patients at both facilities chose those present at their death, which could be partners, immediate family, or sometimes a large gathering of family and friends. Prior to the death, staff visited the patient to say goodbye and patients expressed gratitude for their care verbally, or sometimes, in a letter read to staff after the death. Occasionally however, patients made decisions at the end of life which staff found difficult to implement and which led to conflicted emotions. Nurse Maud highlighted one such occasion involving a child:

*“There was one patient who had a very little child, who was ten years*

*old, and when she died she held him in her arms and that was difficult for me. I don't know if I would do this with my own child.” (Maud: H)*

Many of the assisted deaths described were peaceful, but staff did cite traumatic cases. Dutch healthcare facilities usually provide patients with a single room, but a traumatic death could still impact on other patients. Nurse Famke (CDCC) described such a case:

*“...the room was full. I think we had 12 people around her bed. The emotions were there. When it happened the children held her and screamed and cried. It was in front of the ward [heard throughout the ward] and the other patients they had a hard time that day. They hear the screaming and crying and that was not good.” (Famke: CDCC)*

When a single room was not sufficient to camouflage an assisted death staff had to field questions, and listen to the concerns and views of other patients, whilst being mindful of preserving confidentiality.

Gaining closure after such traumatic deaths could also be difficult for staff. Described by other staff as independent, Nurse Famke, who cited the case immediately above, sought to keep her work and private life separate. She attended the funeral, but highlighted a lack of support to resolve her feelings. It was also the doctor's first case and, although a post-death debriefing went well, personal closure took Famke months with identification of the moment of

closure. Reflecting on her management of this case at length she aimed for more “*peace around the bed*” (Famke: CDCC) next time.

#### **4.5.4 Lethal Medication**

Specific drug protocols need to be followed for an assisted death to be lawful. Doctors are generally responsible for collecting the medication from the pharmacist, but in institutions local policies can apply. Lethal medication was not however, stocked on the ward at the chronic disease care centre, but was prescribed on a named patient basis. Doctor Tim explained the process of obtaining lethal medication:

*“...you write a prescription for a euthanasia kit and then you go to the hospital or, in the city, to the pharmacy of the hospital. You gave the prescription and get a box. You follow the instructions on the inside of the kit and you can make a choice if you let the patient drink the euthanasia or you can also use an infusion.”* (Tim: CDCC)

The medication prescribed is a strong barbiturate, given intravenously to induce coma, followed by a muscle relaxant which works quickly to end life. Staff suggested death usually occurred within seconds. In the Netherlands intravenous delivery of the medication is the commonest form of drug delivery, favoured because it is effective and swift whereas oral medication may not be reliable. Doctor Ilse specified why she favoured this method:

*"... the patient asked me to do euthanasia and the problem with drinking is, when people are very ill sometimes they are going to vomit and when the patient is prepared it has to work with no problems. With the infusion IV it never goes wrong if you do it in a good way."*

(Ilse: CDCC)

Sometimes however, giving lethal medication was emotionally difficult for doctors and after cannulating the patient, they requested help from a more experienced colleague to administer it. A lack of experience, a long standing relationship with the patient and relative youth were cited as reasons for this understandable difficulty. Doctor Liam had experienced this problem. A seemingly confident doctor he expressed satisfaction at achieving a high level of seniority at a relatively young age. Despite being in agreement however, with a patient's request, he had been unable to deliver the lethal drugs himself and sought aid from a more experienced colleague. He explained his difficulty:

*"I'm thirty-two for the record. I can discuss with the patient, with the team and agree it is the best option, but to take away the life in a moment and inject the medication that is something else. I believe I'm not still ready for that."* (Liam: CDCC)

Youth however was not the doctors' only difficulty. Senior doctor Ruben requested assistance to administer lethal drugs to a patient with whom he had become close during the four month assessment process. These issues

highlight that, despite acceptance of assisted dying in principle and a willingness to support patients desires, administering lethal medication can be an emotional boundary which doctors do not find easy to cross.

#### **4.5.5 'It's never normal'**

A theme subjected to latent analysis discussed in Chapter Five (5.2) doctors, nurses and therapists reported that an assisted death was 'never normal' and this was reemphasised by staff at the Open Invitation Research Summary [OIRS]. As Doctor Lara explained:

*"...the rules are quite strict and it is good as it is not a normal medical treatment. It is not normal and patients should be aware of that."* (Lara: CDCC) [OIRS]

For medical staff the post-death procedures required by Dutch law and discussed later (4.6.1) perhaps intensified such feelings, but nurses and therapists also identified a 'strange atmosphere' when a planned death was due to take place. Maud, a hospice nurse, highlighted:

*"It is always a little bit strange that someone is going to die tomorrow at seven o'clock. It is very strange."* (Maud: H)

Several staff discussed the value of discussing such deaths openly not only with each other, but also in a wider context as Doctor Lara explains:

*“It’s not normal for a doctor to kill someone. I think it is good it is still in the media and there is a lot of talking about it.....its good there is constant discussion about it.” (Lara: CDCC)*

Despite the relative longevity of Dutch legislation these quotes suggest that assisted deaths remain an abnormal form of demise for patients viewed through the eyes of staff. Such sentiments about assisted deaths were distinct from conscientious objection as most staff were broadly in favour of patients having the right to choose the manner of their death. A heightened sense of loss was reported by staff when a patient died with assistance. This was emphasised by Nurse Eva (CDCC):

*“It’s not the ‘normal’ way. When somebody dies it is always sad, but that [assisted dying is a little bit more sadness.”*

Despite these feelings however, several staff stated the need to be respectful of the patient’s decision putting the onus on themselves to *“find it a place for it”* (Eva: CDCC) rather than focusing on the patient’s choice of death.

#### **4.5.6 The Use of Humour**

During the interviews staff from all professional groups became emotional as they recalled patients. An offer to stop the interview was made, but the participants declined and, perhaps to relieve the emotion, there was some use

of humour. One participant in particular, a therapist, gave accounts which included such elements:

*“...we are sitting outside and we are writing the cards you send when you are dying [bereavement cards]. But she wasn't dead! ...they give me the card but she is still sitting beside me, but we laugh. In the morning I make her up. And then she asked me in the afternoon if I want to make her up her daughter and her sister ...very beautiful. She said to me ‘I want to see what you make of me’ and she chose her own clothes, her hair, lipstick. I have to manicure her nails with very red polish [laughter], her lips also very red and she very nice sexy underwear, but I have to put on the incontinence pants. The underwear is very small and then the big pants and we laugh about this with her daughter. ‘Oh, well I die...’ but it was a very good day.” (Tess: H)*

In another case she interrupted a family gathering at the planned time of an assisted death to offer freshly made French fries, locally considered a treat. Initially angry, the family sent her away only to call her back a few minutes later so the patient could have a plate of fries before his death which the Tess considered a ‘happy ending’.

#### **4.5.7 Summary: Assisting a Death**

Staff from all professional groups undertook a range of special tasks to meet

the final requests of patients. After saying goodbye the time of death was recognised as potentially stressful, with extra staff or volunteers on the ward to support participating staff. In recognition of the emotional demands, nursing staff looking after the patient were allowed to leave after the death. Obtaining lethal drugs is subject to specific protocols, but some doctors were unable to administer them without the support of a more experienced colleague. Relative youth and inexperience were cited as reasons for this difficulty. Other patients sometimes wanted to talk about the death. Moreover, assisted deaths never felt 'normal' with staff in all professional groups, highlighting a 'strange atmosphere' afterwards although some staff were able to recall some deaths with humour.

## **4.6 Bereavement Care and Beyond**

### **4.6.1 After Death Procedures**

Some doctors discussed the Dutch reporting procedures because a Dutch assisted death is not considered a 'natural death'. Prior to the death the attending doctor informs the local Prosecutor's Office of the planned date and time of death so the body can be viewed. After the death the body, documentation, and the medication used is screened by a 'forensic pathologist' who grants permission for the body to be removed. A death certificate is not

supplied. The explanation from Doctor Ilse (CDCC) below includes the role of the Regional Euthanasia Review Committee:

*“Well, first you have to call the local pathologist because it is not a natural death so you cannot complete a death certificate. You have to fill in a lot of forms and add letters from the physician of the patient and then it goes the Review Committee and they are studying the file deciding whether or not you acted according to the law.”(Ilse: CDCC)*

Some doctors found these procedures onerous, disagreeing with the need for them. Nurses and therapists however, did not mention them even when asked directly, suggesting a lack of knowledge of their existence amongst healthcare disciplines.

#### **4.6.2 Legal or Not? : ‘Waiting for the all clear’**

Doctors identified a stressful period of uncertainty whilst awaiting clearance from the authorities for their actions, as doctor Liam explained:

*“... they [the Review Committee] have all the forms and then after a few months the doctor who performs the euthanasia gets a response ‘Right, he did it correctly’. For a doctor the months are a bit stressful. It can take months.” (Liam: CDCC)*

In complex cases the delays in confirming that their actions had been lawful were considerable for some doctors, with one waiting six months which she considered “*too long*” (Ilse, CDCC). Not all doctors however, were concerned suggesting the current reporting procedures afforded the medical profession protection from prosecution. There was however, some questioning of the legality of assisted dying as every case is subjected to a form of judicial review a procedural ‘loop’ identified by doctor Tim:

*“Well, it doesn't feel OK when you follow the protocol and do something to help a patient and then you are [potentially] prosecuted for murder until they say it is done in a good fashion and you won't be prosecuted. It is a very strange feeling. It's OK they are very strict about it, but I think they have to make it legal. If the protocol is followed you have to make it legal or illegal, but not this strange loop they now use.”* (Tim: CDCC)

There have been no prosecutions of doctors however, since 2002, but Review Committees can highlight cases where deficiencies have occurred and levy disciplinary action against individuals and institutions.

#### **4.6.3 The Emotional Experience and Staff Coping Strategies**

Staff identified feeling emotional after the death. This ranged from a sense of disbelief, to “*relief*” (Maud, H) for the patient, to feeling “*very heavy*” (Emma, CDCC) a word commonly used by staff to describe their emotional response to

an assisted death. At the chronic disease care centre, multidisciplinary debriefing meetings were organised after the death by the attending doctor. Often emotional these were, however, much appreciated by staff and considered valuable for those with less experience. Nursing and therapy staff at the hospice also emphasised the value of talking to each other to gain closure.

After a death at the chronic disease care centre (site A) the on-site psychologist talked to staff who could also book an individual appointment if necessary. For staff working in isolation however, such as solo family doctors, it was suggested gaining emotional support might be difficult. Having supported the patient through illness and the legal process however, some staff felt personal satisfaction in helping the patient achieve their aim:

*“It's strange, but in the cases of a General Practitioner you went all the way with those patients in their illness and it would feel not humane not to give the euthanasia. Then you get the feeling you have done something good for the patient.” (Tim: CDCC)*

This quote suggests that, despite the challenges and the demands, some staff value their role in enabling a patient to achieve their aim of an assisted death. However, Doctor Cornelia, who objected to assisted dying, also suggested the impact of such deaths may not lessen with repeated exposure. To illustrate she cited a colleague who, despite being initially happy to perform assisted deaths,

eventually declined:

*"I had a colleague who was all for it [assisted dying] and she's 'I can't do it anymore' because even if you are in favour of it, it becomes a burden when you do it three or four times. It is stressful to kill somebody."*

(Cornelia: H)

Verification of this was impossible, but interviewed staff who had experienced more than one assisted death did not suggest such deaths became easier.

Additionally, for some doctors like Ilse, there were longer-term effects which influenced their ability to consider new requests:

*"It is not normal and it has a lot of impact. For me it takes a year before I get over it and think 'Ok, now I'm ready for a new trajectory.'" (Ilse: CDCC)*

This suggests that, despite a willingness to care for patients who receive an assisted death, the care demands on staff are high and, without a period of recovery time, their emotional ability to care for another prospective assisted dying patient may be compromised.

#### **4.6.4 Bereavement Care: 'Doing a bit extra'**

Staff from all professional groups altered their normal bereavement practices after an assisted death often *"doing a bit more"* (Famke: CDCC). Bereavement protocols similar to the United Kingdom were evident such as telephone

contact with the family after death to check on their well-being. Partners and children were also invited back to meet with the doctor and nurses a few weeks after the death and sometimes doctors maintained contact with families by email. Such contact “*moments*” (Ruben: CDCC) were highly valued by staff.

Occasionally however, bereavement support went to extraordinary lengths, such as a nurse Abe (H) who maintained contact with a family to field any questions from the patient’s young children that may arise in the future:

*“I’m in contact with the parents of the patient because he [the patient] said to his parents ‘Please stay in contact because when the children are bigger or grown-up they ask questions’ and ‘You can tell them why I did what I did. They have a right to know it’.”* (Abe: H)

When asked if his nurse manager was aware of this he was silent, perhaps suggesting such activities were not encouraged or considered good practice, although he considered it “*an honour*” (Abe: H).

#### **4.6.5 Families and Grieving**

Staff had concerns that assisted deaths led to a more complex grieving process for families due to the swiftness of the death. Hospice nurse manager Gwen who had dealt with many assisted deaths expressed her concerns:

*“... for the relatives it is a very strange death. When you are going to die normally it is process going slowly. In the [assisted dying] process people are talking to you and five minutes they aren't here anymore. I think it's harder to go with your emotions.”* (Gwen: H)

Other nurses cited cases where they felt grieving was difficult for a specific family member such as a patient's Mother, or when the voluntary nature of the death led to conflicted feelings in the family. In contrast doctors were more positive suggesting families, in their experience, were usually “*grateful*” (Lara, CDCC) for their efforts or felt “*relieved*” (Ilse, CDCC).

#### **4.6.6 ‘Never Forgetting’**

Typically, assisted deaths were remembered by staff for a long time, years in some cases, with unexpected events triggering memories, although such recollections were not always a ‘burden’ as Doctor Ruben (CDCC) explained:

*“Still now, when I enter his room I still think of it. Or when I was in Siena in Italy, which is where this patient got married. You will always remember it, but it's not burdensome”.* (Ruben: CDCC)

Nurses were also not immune from the ‘never forgetting’ with Nurse Emma ‘seeing’ the patient when she entered ‘his’ room a year after his death. This suggests that assisted deaths may potentially have a longer term impact on

staff than natural deaths.

#### **4.6.7 Summary: Bereavement Care and Beyond**

After death procedures related to assisted deaths led to some doctors questioning the legality of assisted dying in the Netherlands. Moreover, receiving the 'all clear' in complex cases could take many months, which some doctors found stressful. Staff cited a number of coping strategies to offset the emotional experience including debriefing meetings, talking with colleagues and accessing psychological support. Staff often did 'a bit more' for families bereaved by such deaths, but sometimes they maintained contact and made much longer term promises. Doctors and nurses differed in their perceptions of how the bereaved families coped, but both groups of staff 'never forgot' assisted dying patients with memories triggered by events or places.

#### **4.7 Summary of Chapter**

Multiple interpretations are possible, but using a thematic analysis schema by Braun and Clarke (2006), four main themes *Assessment and Its Challenges*, *Preparing Staff and Learners*, *Assisting a Death*, and *Bereavement Care and Beyond* were identified.

Assisted dying requests were heard by doctors, nurses and therapy staff, but the frequency of requests varied across clinical areas with a high proportion of hospice patients wanting to discuss it. All staff groups explored the seriousness of requests with slight variations in their approach such as focussing on palliative care, unresolved clinical issues or quality of life. Staff valued the openness of dialogue about end-of-life care issues, but patients varied in the openness of their response. The majority of requests, which varied in frequency across clinical specialties, were resolved by measures other than an assisted death.

Personal characteristics common to patients who persisted with a request were identified. These included a desire to be in control, but patients also needed to be articulate, persistent and determined. Palliative care was highly valued and application of its principles a common response to an assisted dying request. For doctors optimising palliation was an important first step in determining if the patient's suffering was unbearable, a key legal criterion recognised as difficult to establish with certainty.

Few staff volunteered an outright conscientious objection to assisted dying, but for those who did, dealing with high volumes of requests was onerous. The

right of objection was applied by some doctors selectively to specific patient groups, such as patients with dementia. Other staff suggested it should be limited to patients with incurable physical conditions. For nurses, instead of a fixed position, objection to assisted deaths was a more fluid concept. If requests were carefully considered by doctors, nurses were more willing to cooperate, but they maintained their right to withdraw if they considered the assessment process, or medical care of a patient, inadequate.

Assisted deaths were demanding, particularly for doctors who needed to ensure legal requirements were met. At the chronic disease care centre a psychologist was described by staff as helpful in assessing the patient's psychological status. Nurses also however, noted fluctuations in the patients' mood with patients having 'good' and 'bad' days. Nurses, despite formal recognition in law, nevertheless played a significant role seeking specialist referrals and alleviated physical difficulties which sometimes altered the patient's mind-set or delayed a death. Doctors and nurses cited patients who decided against an assisted death after it had been granted and went on to enjoy life.

Supportive networks, such as the support and consultation service for doctors, were highlighted as a useful and important resource. Few staff identified any

special professional preparation for assisted dying care, but the value of life and work experience was reported. A need to provide support to learners, such as nursing students, at the time of an assisted death, was identified.

Concentrated efforts were made to meet patients' final wishes, but the death itself needed careful management to ensure the patient, family and the staff were supported. Administering lethal medication was a challenge for doctors with some needing the assistance of a more experienced colleague to complete the task. All staff groups considered assisted deaths as 'never normal' with a strange atmosphere being created on the ward.

The legality of assisted dying was challenged by some doctors because of the Dutch reporting and scrutiny procedures after death. Moreover, waiting retrospectively for their actions to be deemed satisfactory was stressful for some doctors and could be lengthy in complex cases. Staff attended to the bereavement care of families more attentively after an assisted death and sometimes this led to long-term contact with the families of patients. Doctors, nurses and therapists 'never forgot' assisted dying patients with memories triggered by places and events. Resolving their feelings after a difficult assisted death took time, but ultimately they 'found a place' for their feelings. Respecting the patient's decision was a fundamental principle for staff, but some doctors were unable to consider another case for some time.

## Chapter Five: Discussion

### 5.1 Introduction

The constructed reality of Dutch healthcare staff caring for assisted dying patients is discussed in this chapter. The chapter follows the surface level, or semantic (Braun and Clarke, 2006) analysis of themes. In addition some themes have been amenable to more theoretical considerations (*latent* analysis) (Braun and Clarke, 2006). These include 'never normal' (5.2) and, in Ethical Issues (5.5), and the fluctuating support for assisted deaths (5.5.1). Although many interesting themes were generated by the data analysis, thesis size prohibits discussion of all the possible ramifications. Priority has been given to topics which are more novel in terms of the published literature or which add depth, or a new emphasis, to existing knowledge.

Exploration of 'never normal', a construction (5.2) of assisted deaths which arose from all staff groups, starts the chapter. Discipline specific factors which may contribute to this phenomenon, such as the reporting procedures, are also considered (5.2.1). Palliative care is not a medical specialty in the Netherlands, but its relationship to Dutch assisted deaths is discussed in 5.3. The section includes role of nurses (5.3.1), including safeguarding (5.3.1.1) and decision-making (5.3.1.2) followed by the role of therapists (5.3.2). Assisted deaths were challenging for staff (5.4). Notably, administering lethal medication was

impactful for doctors (5.4.1) and this may have implications for staff beyond the Netherlands. Unreasonable demands for assisted deaths were challenging for many staff (5.4.2). Such challenges led to reluctance to consider new requests. This raises equity and equality issues, a new emerging topic in assisted dying, discussed in 5.4.3. After ethical issues (5.5) more practical concerns such as the effect of assisted dying requests on staff workloads are considered in 5.6. The chapter ends with the emotional impact of assisted dying on staff (5.7) followed by the differing perceptions of families and their grieving processes (5.8). The chapter ends with an acknowledgment of the limitations and strengths of the study (5.9) and a chapter summary (5.10).

## **5.2 Assisted Dying: ‘Never Normal’**

Assisted deaths created a ‘very strange atmosphere’ on the wards which was experienced by staff from all the professional groups interviewed. Moreover, they constructed such deaths as ‘never normal’, a theme reinforced by participants at the Open Invitation Research Summary (3.5.1) held to review the provisional findings.

To explore this constructed reality (Patton, 2015) of staff it is useful to consider, as a first step, the concept of a good death. The social history of a good death as charted by Kellehear (2007) is lengthy, but recognition of

approaching death and community involvement, with the dispersal of land and property to ensure future generations prosper, is medieval in origin.

Historically, in contrast to a good death, a 'bad death' was sudden or violent, due to incompetence, or occurred away from home (Kellehear, 2007). Such markers of a bad death persist with a good death, in modern healthcare practice, portrayed as timely, peaceful, pain-free with family and friends in attendance (Komaromy and Hockey, 2001).

It could be argued that assisted dying, which allows patients to prepare and depart at a time of their choosing, meets the criteria for a good death. Writers, such as Vink (2016) for example, suggest a 'self-delivered' demise can constitute a good death. Clinicians in this study identified assisted dying patients as often very ill with refractory symptoms resistant to palliation. Despite their relief the patient was no longer 'suffering', staff perceptions of assisted deaths was that they were abnormal. Notably, this perception differed to an objection on moral or ethical grounds, as a majority of staff were broadly in favour of the Euthanasia Law (TLRAS, 2002). This adds to other studies which highlighted doctors' discomfiture at hastening deaths (Haverkate, van der Heide, Onwuteaka-Philipsen, van der Maas and van der Wal, 2001) and an 'intensity' cited by Belgian nurses (Denier, Dierckx de Casterlé and Gastmans, 2010), but neither identified staff perceptions of assisted deaths as abnormal.

There is a high level of public acceptance for assisted dying in the Netherlands (Cohen *et al*, 2014), but staff perception of assisted deaths as abnormal may serve a useful purpose in clinical practice. Database searching suggests the conceptual analysis of 'normalcy' is limited, but it has been linked to statistical prevalence (Kahane and Savulesca, 2012). Seeing assisted deaths as abnormal may reinforce in staff and patients' minds that such deaths are an exceptional rather than a normal everyday occurrence. This appears to prompt rigorous attempts to find alternative options such as palliation, the instigation of practical measures to overcome disabilities and intensive questioning of the patient's reasoning. Such activities all help to ensure that requests are considered with the upmost care.

This is important as the numbers of Dutch assisted deaths have risen over time, and accounted for 4.1% of all Dutch deaths in 2016 (Royal Dutch Medical Association, 2017). Gamondi *et al* (2014) have highlighted the potentially moderating effect of allowing only self-delivered deaths (physician-assisted suicide), as most patients will prefer death delivered by a healthcare professional (euthanasia) if available. This might help to reduce the incidence, but globally, where figures are publically available, numbers continue to rise for all types of assisted death, although these remain a relatively small proportion of all deaths (Emanuel *et al*, 2016). These figures may of course plateau in the future but, if not, assisted dying may statistically become a more 'normal' form

of death, potentially increasing the risk to patient and staff well-being.

There are however, challenges to the staff construction in this study of assisted deaths as 'not normal'. Active supporters of assisted dying such as Kathryn Tucker (Tucker, 2015) who, as a lawyer will not have to perform it, argue assisted dying should become "*normalised*" (p.3) within medical practice. Recent legislation in Canada (Parliament of Canada, 2016) has adopted the term 'Medical Assistance in Dying' (Government of Canada, 2017) with the reassuring sounding acronym of MAiD. Such linguistic alterations matter because constructionism suggests (Burr, 2015) that language usage will influence how experiences are structured by patients and staff. Furthermore aligning assisted dying to medical practice increases the pressure on staff to participate and may enhance its credibility as an option.

An alternative view, as espoused by Taylor and Martin (2014), is that healthcare staff should support patients' end-of-life choices wholeheartedly. There are challenges to the idea that it is successful (Rothstein, 2014), but modern health policy encourages patients to make autonomous decisions about their care (Entwistle, Carter, Cribb and McCaffery, 2009). Moreover, improvements in medicine such as life support technology reinforce the idea that a death can be controlled (Kellehear, 2007). This does not however,

acknowledge that patients do not always make wise choices and, as this study highlights, some Dutch patients will change their mind even after successfully negotiating the assessment criteria. Actions that normalise assisted dying, acting against the abnormality of assisted deaths as experienced by staff, may negate a mechanism that currently, albeit tentatively, safeguards all patients.

### **5.2.1 Contributory Factors: Legal or Not?**

Despite its relative historical longevity, the Dutch procedures for reporting and scrutiny led some doctors to question the legality of assisted dying in the Netherlands. The Dutch reporting procedures have been described as “*semilegal*” by Kimsma and van Leeuwen (2012, p.192), but their impact on doctors is rarely considered in the literature. Doctors are unable to complete a death certificate and report deaths to the Public Prosecutor’s Office. This can result in a visit to the scene by the police (Vink, 2016) albeit in plain clothes. This procedure was described by a doctor in this study as a ‘strange loop’. This is apt because his actions, when performing an assisted death, are ratified by law and then considered unlawful, until proven otherwise. Doctors can of course decide not to report an assisted death, but this would constitute an illegal act.

Since the 2002 Act no Dutch doctors have been prosecuted (Griffiths *et al*, 2008), a fact espoused by those in favour of assisted dying and those against (Keown, 2012). Doctors can however be asked to appear in person before a Review Committee (Griffiths *et al*, 2008) and disciplinary action can be levied against doctors and institutions (Griffiths *et al*, 2008). This includes a jail term of up to 12 years for euthanasia and three years for assisting a death if prosecuted (Government of Netherlands, 2017b). The reporting rates of assisted deaths have however, quadrupled since the 2002 law (Rurup *et al*, 2008). This suggests that some doctors, despite clearance delays, do have faith in the system with some expressing this view in this study.

A lighter approach to non-complex cases has been adopted since data collection for this study (2013) reducing the average wait to thirty-nine days in 2015 (Review Committees, 2016b). Doctors in this study however, expressed anxiety about the more complex cases perhaps because they may be more likely to be seen as contentious. Notably, case complexity did not deter some patients from being persistent in their request highlighting the challenges of applying prescribed legal criteria to the real situations as experienced in clinical practice.

The Dutch reporting procedures differ from those in Belgium (Griffiths *et al*, 2008) where doctors can complete a death certificate and self-report to the Federal Control and Evaluation Commission within four working days (Kidd, 2002). Similarly self-reporting within eight days is permitted in Luxembourg (Thill, 2015). As in the Netherlands scrutiny of each case occurs (Griffiths *et al*, 2008; Thill, 2015), but there is no immediate review of the body by the judicial system. In the United States, where confidentiality of the doctor and the patient are a concern (Ganzini *et al*, 2000), assisted deaths are considered 'natural' and a death certificate is supplied by the doctor stating this (Dunn *et al*, 2008).

As noted in the Review Committee Annual Report of 2015, an appraisal of the work of the Review Committees has been ongoing. A final report is due and may include consideration of some of the issues raised here. Worthy of consideration is aligning the Dutch reporting procedures with those of Belgium and Luxembourg where the doctors are required to self-report an assisted death directly to the reviewing authorities. In Belgium (Jones, Gastmans and Mackellar, 2017) there remains a concern about non-reported cases. The country lacks, Nys (2017) suggests, an efficient death registration system and the historical onus on Dutch doctors to report assisted deaths which pre-dates the current Dutch law (TLRAS, 2002). The latter may help protect the Netherlands from some of the concerns raised in Belgium, but non-reporting

remains a commonly voiced concern (Onwuteaka-Philipsen, 2012) and it is impossible to be certain.

### **5.3 Assisted Dying and Palliative Care**

The constructed reality of staff suggests assisted dying is not an anathema to palliative care with all staff groups emphasising the use of its principles in practice. There were however, subtle differences in the use of palliative care between staff groups. Nurses cited its use in promoting open dialogue to explore reasoning behind a request, to alleviate physical suffering and to promote comfort. Doctors, after an assisted dying request, aligned their use of palliative care principles more closely to establishing if all attempts had been made to make the patient's suffering 'bearable'. This probably reflects the differing requirements on staff in terms of the law. It also acknowledges however, the difficulties for doctors in establishing if suffering is 'unbearable', a concept that it has proved difficult for both patients and doctors to define (Dees *et al*, 2010; Pasman *et al*, 2009).

Assessment of the use and impact of palliative care in the Netherlands is complicated by the fact that it is not a medical speciality (Willems, 2012). In the United Kingdom Specialist Palliative Care has been defined (National Health Service England, 2016) as being:

*“delivered by a multidisciplinary team of staff with the requisite qualifications and experience in offering care for this group of people”*  
(p.6).

In contrast palliative care in the Netherlands is seen as generalist activity (Agora, 2015) with resources focused on up-skilling all staff (Agora, 2017). The biographies (Appendix 8) of the interviewed hospice staff illustrate their extensive experience in end-of-life care. The hospice however, did not have the comprehensive multidisciplinary team, or outreach services, associated with a specialist palliative care facility in the United Kingdom. In comparison, more comprehensive services were available and utilised by assisted dying patients at the chronic disease care centre, despite its specialist function relating to respiratory, rather than palliative care. Such issues confound comparisons of the availability of palliative care for Dutch patients.

Nonetheless, this study has highlighted that palliative care has a high profile and is highly valued by Dutch staff with an assisted death request triggering its use. This is supported by Onwuteaka-Philipsen, Rurup, Pasman and van der Heide (2010) who identified that Dutch assisted dying patients were more likely than other dying patients to be seen by pain, palliative care or mental health specialists. Dutch palliative care has also been strengthened significantly across a range of providers (Willems, 2012; Brinkman-Stoppelenburg, Boddaert,

Douma and van der Heide, 2016) since a descriptive appraisal of service providers by Francke and Kerkstra in 2000. For some staff however, that permissive assisted dying legislation was enacted before the development of palliative care was a cause of frustration. This applied particularly to staff who objected to the option of an assisted death. This cannot now be undone, but it reinforces the notion that staff knowledge of palliative care principles should be as robust as possible before the implementation of assisted dying legislation.

### **5.3.1 The Role of Dutch Nurses**

This study has highlighted previously unreported activities undertaken by Dutch nurses. In some aspects there are commonalities with qualitative research from Belgium by Dierckx de Casterlé *et al* (2010) such as their role in receiving requests and participating in the decision-making. This study however, has highlighted that these activities are much wider ranging and nuanced than suggested in previous Dutch survey research (van Bruchem-van de Scheur *et al*, 2008a; Francke *et al*, 2016). Nurses instigated specialist referrals, met complex final requests, and, when present, actively managed deaths to minimise the impact on observers and other patients. As discussed below (5.3.1.1) they also have a potentially powerful role in safeguarding patients and should be included in the decision-making process (5.3.1.2).

### **5.3.1.1 Safeguarding Patients**

Assisted dying is a dynamic phenomenon with new legislation, albeit as a slow trickle, appearing almost annually. Absolute certainty cannot be attributed to any of the findings of this research, but nurses appear to fulfil a safeguarding role previously unacknowledged. The perceptions of patients were not collected in this study, but staff suggested that whilst some patients were firm in their assisted dying request, others were amenable to alternatives if suggested by staff. This is important as, although the media portrayal of assisted dying often focuses on patients with a firm and longstanding desire, this study suggests some consider an assisted death 'too easily'. Instead of taking requests at face value however, the nurses invested time and effort exploring seriousness and suggesting alternatives which sometimes altered the patient's mind-set. Hypothetically, this suggests that nursing interventions are potentially powerful influencing the patient's chosen pathway. Whether or not such activities are recognised by staff as an important safeguard remains to be established, but recognition of the pivotal nature of nursing interventions is warranted where legislation is being implemented.

Moreover, the terms of legislation may extend the potential influence of nurses. Dutch legislation, in common with legislation in the other Low Countries (Kidd, 2002; Ministry of Health, 2009) and more recently Canada

(Parliament of Canada, 2016) permits assisted dying without a fixed likely prognosis. This opens up the possibility of long-term dialogue with patients particularly those with chronic, but incurable disease. Nurses in this study cited having conversations with such patients for months, or even years, before an assisted death. In Belgium palliative care is often cited as an 'accompaniment' (Vanden Berghe, Mullie, Desmet and Huymans, 2013) to assisted dying, but this study suggests that dialogue about an assisted death in chronic disease can run alongside 'everyday' care for a significant length of time. Nurses working with 'open-ended' legislation (Parliament of Canada, 2016) may need prepared for ongoing dialogue about assisted deaths, but should also recognise their valuable role in delaying death by providing practical and supportive measures to overcome problems such as mobility loss, incontinence or feeding difficulties.

Moreover, Dutch nurses may safeguard patients in other ways despite a lack of recognition within assisted dying legislation (TLRAS, 2002). The assessment of mood at the end of life is problematical and an area of contention internationally (Wasteson *et al*, 2009). If depression is suspected psychiatric assessment is mandatory (TLRAS, 2002), but this study has identified that nurses may also play a significant role in assessing the psychological status of patients requesting an assisted death. Continuity in their care facilitated nurses' observations of the emotional status of patients with recognition that patients have 'good' and 'bad' days influencing their decision-making about an

assisted death. American (Ganzini, Goy and Dobscha, 2008) and Dutch research (Ruijs, Kerkhof, van der Wal and Onwuteaka-Philipsen, 2011) is conflicted on the incidence of depression in assisted dying, but Finlay and George (2011) suggest its presence may increase patients' vulnerability. This study sheds no light on whether or not patients requesting an assisted death were depressed. However, staff highlighted that psychological status, even if not diagnosed as clinical depression, may influence the patient's decision-making and therefore, it warrants ongoing review.

It could be argued that nurses who lack a formal psychiatric qualification are not adequately trained to assess psychological status. At the chronic disease care centre (site A), patients making an enduring assisted dying request were assessed by the on-site psychologist. Unfortunately, this study failed to recruit a psychologist which might have strengthened the findings. Although attitudes and the potential role of psychologists has been explored (Fenn and Ganzini, 1999; Sears and Stanton, 2001; Johnson, Crammer, Conroy, Gardener, 2014) empirical study of their work with such patients appears to be lacking. Further research of Dutch psychologists work with assisted dying patients may therefore, be informative. However, this study has highlighted that nurses are in good position to observe patients and initiate psychological referrals. This may safeguard some patients.

### 5.3.1.2 Nurses' and Decision-Making

Nurses at the chronic disease care centre (site A) valued careful, transparent and multidisciplinary decision-making of assisted dying requests, a finding supported by Belgian research (Dierckx de Casterlé *et al*, 2010). Dierckx de Casterlé *et al* (2010) also identified that a lack of multidisciplinary working could effectively exclude nurses from the decision-making process. Dutch research (van Bruchem-van de Scheur *et al*, 2007) lends some support for this idea, notably in primary care where doctors and nurses work separately. Dutch home nurses were only consulted in 41.2% of assisted dying cases compared to 78.8% of their hospital counterparts (van Bruchem-van de Scheur *et al*, 2007).

Such a lack of consultation with nurses may have occurred at the hospice (site B) in this study. Van Bruchem-van de Scheur *et al* (2007) and Verschuur, Groot and van der Sande (2014) suggests Dutch nurses are becoming more professionally proactive, but in this study a lack of consultation left them coping with assisted deaths which, the appropriateness of some, they doubted. It is beyond the remit of this study to explore in-depth the concept of moral distress (Corley, 2009), but end of life issues are recognised as a trigger that may challenge wellbeing (Whitehead, Herbertson, Hamric, Epstein and Fisher, 2015). Hypothetically, attending deaths with which they do not agree may distress nurses (Corley, 2009) and impact on their psychological well-being. It may also reduce the level of support available to the patient and their family at

a critical time. To avoid conflicted feelings this study suggests that nurses, if willing to participate, should strive to be included in decision-making process.

### **5.3.2 The Role of Therapists**

Some therapists in this study were active in assisted dying cases, but as highlighted in the literature review (2.8.4) their activities have not previously been reported. This study clarifies the key role of a Dutch social worker who, if available and willing to participate, can prepare the patient's family including children. An appraisal of the family's needs may be valuable, as this study suggests that even if supportive of the patient's choice, families may have conflicted feelings about the manner of the death. Other therapists, such as creative and activity therapists, were also active in meeting final requests. Therapists from other disciplines, such as physiotherapists, and speech and language therapists, were less involved, but nonetheless, heard expressions of interest and had conversations about assisted dying with patients.

This study adds detail to the reported role of therapists in other jurisdictions, particularly for social work. In Oregon, Ganzini *et al* (2002) highlighted the social worker's role in facilitating the patient's decision-making and their willingness to continue care despite the patient's death choice. Norton and Miller's (2012) later qualitative study suggested that, despite the passage of

time to embed assisted dying into practice, this area of care was still challenging and contentious for social workers. Moreover, Norton and Miller (2012) suggest that, in the United States, the role of the social worker in assisted dying still lacks clarity and is subject to local controls levied by other staff and their institutions, but their findings are limited being based on a single focus group.

At the Dutch hospice in this study there was no on-site social worker. In contrast to Norton and Miller's (2012) study, the social worker at the chronic disease care centre was very clear about the nature and boundaries of her role whilst she assessed and supported families. Such clarity may arise from the construction of assisted dying as an accepted practice in the Netherlands with a high level of public support (Cohen *et al*, 2014). In the absence of other published studies it is difficult to be more assertive, but the support of a social worker may aid the adjustment of families affected by an assisted death. Further exploration of this role in detail may be helpful.

Recognition that some therapists may have a useful role in assisted dying may however, have previously unrecognised consequences. Notably, it increases the range and numbers of staff that require preparation, education, and access to psychological support if permissive legislation is implemented. The

preparation required by practitioners is also likely to vary by discipline which adds complexity. Social workers, for example, if willing to participate, may have a more demanding role (Ganzini *et al*, 2002, Norton and Miller, 2012) than a physiotherapist, who may only receive and need to explore an initial request. Training and support will need to reflect this diversity in roles. The financial cost of assisted dying is rarely considered in debates, but a cost analysis by Trachtenberg and Manns (2015) suggests that implementation of MAiD in Canada (Parliament of Canada, 2016) will be cost-neutral. Basing this notion on the reduced use of acute care services their calculations however, do not include the initial preparation, training and education, and ongoing psychological support of staff. Hypothetically, it is possible that the implementation of assisted dying, which should include therapists, may incur additional costs which are not recognised or openly acknowledged.

#### **5.4 Challenges in Assisted Dying**

End-of-life care is recognised as demanding for staff, particularly doctors (Dréano-Hartz *et al*, 2016) and nurses (Sandgren, Thulesius, Fridlund and Petersson, 2006), but assisted deaths make additional demands on staff. Specifically the administration of lethal medication was identified as emotionally impactful by doctors (5.4.1). For both doctors and nurses, patients who demanded an assisted death, for reasons that were not always clear to staff, were also challenging (5.4.2). The impact of an assisted death also

affected the ability of doctors to consider new cases and this is discussed in equity and equality issues (5.4.3).

#### **5 4.1 Administering Lethal Medication**

The emotional impact of performing assisted dying on doctors has been reported in the United States (Emanuel, Daniels, Fairclough and Clarridge, 1998), but this study adds more detail from the perspective of Dutch doctors. The efficacy of oral lethal medication can be unpredictable (Groenewoud *et al*, 2000; Emanukel *et al*, 2016). For this reason doctors in this study favoured administering lethal medication intravenously, although ingestion by swallowing or through a feeding tube is also permitted (Royal Dutch Medical Association and Royal Dutch Pharmacists Association, 2012). Staff in this study identified the intravenous route as swift causing death within seconds, or less often within a few minutes. Some doctors however, were unable to deliver lethal drugs and sought assistance from a more experienced colleague for this final act. Repeated administration of lethal medication was also linked to doctors withdrawing from work at the hospice because of its emotional impact.

A Dutch qualitative study by van Marwijk *et al* (2007) lends some support to these findings. This study reports that doctors can experience a range of emotions when giving lethal drugs by injection for the first time, including

tension before, loss during and relief after the event. This paper is frequently cited as few studies review this issue, but there are methodological issues to consider. Notably, data from one focus group was lost and a fixed coding frame for data analysis (van Marwijk *et al*, 2007), designed prior to the focus group, may have hindered new insights. These issues led to a lower appraisal score (Summary Table, Appendix 4). Guidance for doctors however, (Royal Dutch Medical Association, 2011; Royal Dutch Medical Association/Royal Dutch Pharmacists Association, 2012) lacks an acknowledgement of the impactful nature of delivering lethal medication, a knowledge gap also reported in staff guidance from Oregon (Dunn *et al*, 2008).

It is also possible however, that differing methods of lethal drug administration have different levels of impact. Concern was expressed in this study that doctors working at the End of Life Clinic (Snijdewind *et al*, 2015) may perform assisted deaths in rapid succession, with six cases in as many months quoted. Snijdewind *et al*'s (2015) paper reviewing the clinic's first year of operation lacks such information, but clinic's Annual Report of 2015 (End of Life Clinic, 2015) highlights that 12% of the clinic's cases were physician-assisted suicide rather than euthanasia. This is much higher than the national average of 4% in the same year quoted by the Review Committees (Annual Report, 2015, Review Committees, 2016b). Physician-assisted suicide, ethicists argue (Materstevedt and Bosshard, 2011), leaves the moral responsibility for the death with the

patient. This may make physician-assisted dying less impactful for staff to administer, hence its popularity at the End of Life Clinic. Further research may be able to clarify whether this 'benefit' is an actuality or whether the clinic's heightened incidence of physician-assisted deaths is due to other issues.

Notably, in this study, some younger doctors reported an inability to deliver lethal drugs, citing relative youth and inexperience as contributing factors. This is perhaps understandable, but a close relationship with a patient also impacted on some senior doctors. Staff may, of course, exercise their right to conscientious objection, but greater recognition of the demands of lethal drug delivery may be helpful for other staff groups. Recent Canadian legislation (Parliament of Canada, 2016) permits nurse practitioners to prescribe and administer lethal drugs subject to provincial and territorial policies, and standards (Canadian Nurses Association, 2017). Publication of this study's conclusions may help to raise awareness of the potential impact of lethal drug administration and the need to instigate proactive measures to support participating staff.

#### **5.4.2 Demands for an Assisted Death**

Staff in this study appreciated the benefits of open dialogue about 'ways of dying', although patients or relatives who **demand**ed an assisted death were perceived by doctors and nurses as difficult. Demands sometimes arose from

relatives anxious to spare loved ones unnecessary distress in the final stages of a terminal illness. In this context staff reported exasperation that relatives did not realise an assisted death was not possible at this late stage. Staff also reported difficulty when patients demanded an assisted death for reasons which were unclear to them.

Self-determination is an important concept in healthcare practice (Collins, 2014) linked to autonomy which literally means 'self', from the Greek *autos*, and *nomos* from the Greek for 'rule' or 'law' (Beauchamp and Childress, 2013, p.101). A qualitative study from the United States by Dobscha *et al* (2004), reported that assisted dying patients were 'determined' and 'independent' in values and philosophy. Similar characteristics were suggested by staff in this study, who also added that patients who obtained an assisted death were articulate, and often well-educated. Unlike in the United States (Emanuel *et al*, 2016), Dutch official statistics do not officially publish data on the patient's educational level so assessing the accuracy of staff perceptions in this study is impossible.

Anne-Mei The (2002) offers a more sympathetic view in a Dutch ethnographical study of patients with lung cancer, although the study was not specific to assisted dying. The (2002) suggests that terminally-ill patients attempt to claim

back control after the failure of treatments which they had passively accepted with the expectation of cure. Characteristically, dialogue with health professionals about care options had been optimistic which patients, with a lack of specialist knowledge, accepted at face value. That these 'therapies', a term which The (2002) highlighted as ambiguous, proved unfruitful was not however, a surprise to the doctors (The, 2002) who may have been 'economical with the truth' when talking to patients.

More research is needed, but assisted dying may be an opportunity for some patients to gain back control after feeling they have been failed, or even misled, resulting in demands rather than a more reasoned request. Viewing patient requests in this way may help staff to explore the patient's reasons for their insistence on an assisted death, but further research focussing on the perceptions of patients themselves may be informative.

### **5.4.3 Equity and Equality Issues**

Assisted dying cases were exacting and placed significant demands on staff. Ultimately this impacted on the ability of some staff to consider assisted dying requests from other patients, with one doctor requiring a 'recovery' period of a year after a complex case. This raises equity and equality issues in assisted dying on which, as Harman and Magnus (2017) concur, there are relatively few

papers. In a rare paper raising the issue, Sneddon (2006) discusses the inequality of access for patients with disabilities if they are unable to self-administer medication, but this is not applicable to the Netherlands as euthanasia is permitted (TLRAS, 2002). It is perhaps however, ironic that equality of access may be impaired if a doctor is unable to assess a case because of fatigue or emotional stress.

Professional guidance (Royal Dutch Medical Association, 2011) suggests doctors unable to consider a case should refer to a colleague willing to do so. Practically however, in geographical areas with predominately single-doctor practices such as the area where this study was conducted, gaining an alternative medical opinion may be difficult for patients. Moreover, doctors in this study suggested that not all their colleagues were open about their stance towards assisted dying and may block dialogue. Other studies (Dobscha *et al*, 2004; Georges *et al*, 2008) supports the view that doctors may avoid dialogue about assisted dying for many reasons, including the enormity of the topic and not agreeing with the patient's perspective.

It is debatable whether or not 'blocked dialogue' has the same impact as a refused request, but Pasma (2012) suggests that after a refused request patients may retain a desire to die. Hypothetically, this may drive patients to

other care providers such as the End of Life Clinic (Snijdewind *et al*, 2015), whose case numbers have increased steadily since its inception (Royal Dutch Medical Association, 2017). In this study there was no suggestion by staff that this clinic operated outside of the law and, in its first year, the clinic rejected 46.5% of all requests (Snijdewind *et al*, 2015), but several staff expressed concerns. Specifically, their concerns related to the clinic's lack of long-standing knowledge of the patient and of their social background, such as might be known by a family doctor. This lack of care continuity, it was suggested, might compromise patient safety. There were also concerns that the clinic's staff might not be adequately competent for the complexity of the work. Assessments of these issues were however, beyond the remit of this study, but issues related the equity and equality of access to Dutch assisted deaths were raised.

## **5.5 Ethical Issues**

Only one participant in this study, a hospice doctor, expressed a firm moral objection to assisted dying. This might suggest that the remaining staff at both sites were in favour of assisted dying, but their views were more nuanced and demonstrated gradations of support for assisted dying.

### 5.5.1 Shades of Support and Cognitive Dissonance

Questioning of staff in this study included their stance of assisted dying. (Appendix 8). Some staff expressed being strongly in favour, but others added a qualifying statement which suggested gradations of support. Qualifying statements included being 'more in favour than not' and supporting assisted deaths for physical illness only. Some staff were 'happy' to discuss it, but doubted it was the patient's best option. Some nurses looked uncomfortable and evaded the question of being in favour or not. When asked directly if they agreed with assisted dying in principle, they responded 'yes', but qualified this by reinforcing their faith in the doctors to proceed carefully when considering requests. Other nurses reported that some of their 'older' colleagues found assisted dying cases difficult.

A psychological theory '*cognitive dissonance*' (Festinger, 1957), initially developed to explore anxiety and social influence, might help to explain some of the discomfort observed in staff. Cognitive dissonance postulates that individuals with conflicting ideals will rationalise an imperfect situation and strive for internal consistency. This is coined *consonance*. If rationalisation is impossible a state of aversive arousal or psychological discomfort called *dissonance* (Festinger 1957, p.2) may occur and individuals may attempt to restore consonance by avoiding situations or activities likely to cause it by altering attitudes (Foster and Mistra, 2013) or even by misremembering past

events (Bølstad, Dinas and Riera, 2013; Rodriguez and Strange, 2015). Festinger (1957, p.2) also postulates that the magnitude of the dissonance is related to the importance of the elements with the most cognitive work occurring at the point of most resistance.

Database search has revealed a single relevant study linking cognitive dissonance to assisted dying. Mitchell's (Mitchell, 2002; Mitchell, 2004) Doctoral study focused on medical end-of-life decision-making. Using qualitative methodology Mitchell (2002) considered cognitive dissonance theory when exploring the psychological impact of euthanasia on two groups of five Dutch doctors. One group of doctors had performed assisted deaths, whilst the other group had not. Whilst both groups valued palliative care, doctors who did not perform assisted deaths, stressed their non-abandonment of, and their continued commitment to the patient. These doctors viewed other actions that might hasten death, such as increasing drug doses or sedating patients, as equally impactful on themselves as an assisted death. Doctors who had performed assisted deaths saw it as the 'ultimate' commitment to the patient, but distinctly different in its impact to other actions that might hasten death. This supports the findings of this study that assisted deaths differ from natural deaths in their impact on staff.

In Mitchell's study (2002) to reduce dissonance effects of hastening death, defence mechanisms were used and both groups of doctors rationalised their actions by constructing their chosen options as palliative only (non-participating doctors) or by justifying it as a necessity to relieve suffering (participating doctors). The 'necessity' justification is not surprising because Mitchell's research was conducted prior to the current Dutch Euthanasia Act (TLRAS, 2002), when necessity (*overmacht*) was a key requirement in law. This issue highlights a limitation of Mitchell's (2002) research namely that it explores doctors' experiences prior to the current Dutch legislation. Moreover, Trappenburg and Oversloot (2012) suggest professional hierarchies may inhibit non-medical staff from raising an objection openly. It is possible however, that staff may use qualifying statements towards assisted deaths as a means of reducing the dissonance effects of their participation.

## **5.6 Workload Issues**

Of concern is the significant workload assisted dying requests generated for the hospice staff in this study. That only a minority of requests resulted in an assisted death is a well-known phenomenon (Jansen-van der Weide, Onwuteaka-Philipsen, van der Wal, 2008), but all requests needed to be explored for the seriousness of their origin by staff. Apart from the on-site doctor who conscientiously objected, staff did not appear to resent this work. This may be because it has become a constructed everyday reality (Berger and

Luckman, 1966) in the minds of Dutch staff. Nevertheless, jurisdictions considering the implementation of assisted dying should anticipate a significant increase in workload for providers of end-of-life care.

Also of interest were reports by doctors of disproportionately fewer assisted dying requests from respiratory patients, in comparison to a high incidence, in haematology. Papers focused on the end stage symptoms of respiratory (Janssen, Spruit, Uszko-Lencer, Schols and Wouters, 2011) (Netherlands) and haematology patients (LeBlanc, Smith and Currow, 2015) (Western Australia) suggest high symptom burdens for both these groups of patients. Official statistics confirm that respiratory disease accounts for only 3.75% of assisted deaths with cancer (including haematology) accounting for 73% (Royal Dutch Medical Association, 2017). Exploring this anomaly might help to identify physical and existential issues that result in requests for an assisted death.

## **5.7 The Emotional Impact of Assisted Deaths**

After an assisted death doctors and nurses typically remembered the case and the circumstances surrounding the death for a long time, even years in some cases. Staff memories of the patient were triggered by places or events although staff did not see this as a burden.

Although there is evidence of the psychological impact of natural deaths on care staff (Wenzel, Shaha, Klimmek and Krumm, 2011; Tranter, Josland and Turner, 2016; Boemer, Burack, Jopp and Mock, 2015) research related to the psychological impact of assisted deaths is lacking. In American oncology (Wenzel *et al*, 2011), after a death, nurses experienced a “*work-related*” loss (p. e275) with a need for self-care, team and organisational support (Wenzel *et al*, 2011). Although the goal in an oncology setting is to sustain life, rather than instigate it, notably the reported psychological experience is similar.

The need to prepare healthcare students for the psychological impact of an assisted death was highlighted in this research. Other studies suggest nursing students (Heise and Gilpin, 2016), and less experienced nurses, find deaths more impactful (Trantor *et al*, 2016). Neither of these two papers are linked to assisted dying, but close relationships with patients heightened the impact of the death (Boermer *et al*, 2015, Tranter *et al*, 2016). Dutch staff in my study developed close relationships with assisted dying patients and their families which developed over the weeks, or months, of assessment. After the death contact with the families was valued, but some staff also made long-term commitments suggesting that assisted deaths may have a heightened impact for staff.

Practically, some staff interviewed found debriefing sessions, after an assisted death, helpful and there is evidence, relating to natural deaths, that such discussions can support staff (Tranter *et al*, 2016). Structured debriefing has also been shown to aid the development of the clinical reasoning skills of nurses (Thomas Dreifuerst, 2012). Exploring its potential in reducing the impact of assisted deaths for staff may be informative. Participants in this study also cited psychological support from a line manager, the availability of a psychologist and organisational employee support programmes, as valuable. This would suggest that access to such services should be available to staff in jurisdictions implementing assisted dying legislation.

## **5.8 Staff Perceptions of Families' Grief**

The perceptions of staff differed by staff group in their view of the impact of assisted dying on families. Doctors reported that families generally coped well, but nurses were more circumspect, suggesting that relatives found such deaths 'strange'.

As reported by Fish (2017) research on the grieving process of families who have experienced an assisted death is limited. Database searching has failed to find any relevant Dutch studies of bereavement which include assisted dying. Cleiren and Van Zoelen (2002) suggest Dutch families fare well after life

support is ceased prior to organ harvesting, a comparably swift mode of dying, but this experience may differ from an assisted death. Contradictory evidence exists from other jurisdictions on whether or not assisted dying families are better prepared (Swarte, van der Lee, van der Bom, van den Bout and Heintz, 2003; Ganzini, Goy, Dobscha and Prigerson, 2009). Wagner, Müller and Maercker (2012) identify higher levels of Post-traumatic Stress Disorder, but lower levels of complicated grief. Gamondi, Pott, Forbes and Payne (2015) have also reported that relatives of patients in Switzerland can be socially isolated because of the stigma attached to assisted deaths.

Focusing on the experience of Dutch staff has highlighted that doctors and nurses may view the well-being of family members after an assisted death from different perspectives. Doctors suggested that families were grateful or relieved, but nurses felt it was 'harder' for families to move through their grief. Such perceptual differences may arise because of their differing roles, but it may also reflect differing perceptions of grief beyond assisted dying which may warrant further study.

## **5.9 Strengths and Limitations**

This study reports the experiences of staff from a request for an assisted death to beyond the death. This may provide useful information to those who wish to

argue against, to participate in, or who need to consider the pros and cons of assisted dying legislation. It is unique in reporting the experiences of more than one staff group from a range of disciplines, highlighting the commonalities, role specific challenges or differing emphasis, of their practice. It widens the assisted dying debate from the plight of individuals discussed in the Chapter One (1.2) to consideration of the preparation, training and education, and psychological support needs of staff who implement such policies. As a qualitative study it reports in greater detail than previously the challenges of assisted dying for doctors, the important safeguarding activities of Dutch nurses, and the roles played by some therapists. It highlights fluidity in the stance of healthcare staff towards assisted dying even when they do not have a moral objection. It raises important issues about psychological support for staff, the availability of palliative care knowledge, workloads, and the financial cost of implementing legislation. Moreover, it identifies several areas which may warrant further investigation including the role of psychologists, the emotional impact of administering lethal medication, equity and equality of access, specialty variation in request numbers and the grieving process for families.

Assisted dying in the Netherlands is however, an ethically contested practise subjected to criticism from abroad. This may have impacted on the information staff wanted to divulge. Staff loyal to the practice, may have been constrained

in their honesty, or moulded their accounts, to suit an unknown purpose. Although some aspects may be transferable to similar situations elsewhere, qualitative inquiry is not generalisable. This study only provides a snapshot of staff experiences and views can change. Staff may therefore, construct their experiences differently with another researcher at another time. Complete researcher neutrality is impossible, but the process of data interpretation has been made as transparent as possible. The interpretations made however, relate to this sample of staff and this researcher. In common with other assisted dying studies few staff openly objecting to its practice were recruited. It is a significant limitation that their perceptions are not included. The study also failed to recruit a psychologist and spiritual advisor who may fulfil important roles. Direct transferability of the findings to other jurisdictions cannot be guaranteed, but some findings may find resonance in jurisdictions implementing similar legislation where staff have similar roles.

## **5.10 Summary of Chapter**

Analytical procedures (Braun and Clarke, 2006), with the development of semantic and latent themes derived from the data, has provided topics worthy of discussion. Constructivist and interpretative exploration of staff experiences, with some findings linked to existing research and theoretical concepts from other fields of study, has offered new insight into the Dutch staff experience of assisted dying.

Assisted deaths in the Netherlands are voluntary by definition (TLRAS, 2002), but despite the maturity of Dutch legislation such deaths were not perceived as normal by staff. This may be a useful mechanism activating scrutiny of seriousness and the resolution of physical and existential problems which altered the mind set of some patients. Such safeguarding is necessary with doctors and nurses citing cases where patients were later grateful for a longer life. Narratives advocating the normalisation of assisted dying as a medical procedure may operate against this potential safeguard.

Globally the provision, configuration and the status of palliative care varies. Palliative care in the Netherlands is not a medical specialty reducing its visibility in education and research. Staff however, used the principles of palliative care in promoting open dialogue, alleviating suffering, resolving existential issues and offering patients an alternative to an assisted death. Despite a lack of legal recognition Dutch nurses were very active receiving requests, exploring reasoning, seeking specialist referrals and resolving practical problems. In some patients with incurable chronic disease this delayed their assisted death. Apparently previously unreported, some Dutch therapists were also very active, including a social worker, a creative therapist and an activity organiser. Other therapists received and made an initial assessment of requests and supported their colleagues at the time of death.

Assisting dying cases were challenging for staff. Administering lethal drugs challenged for doctors particularly the less experienced or younger doctors. The impact of repeated lethal drugs administration appears to be unknown. Demands for assisted deaths frustrated staff. High numbers of assisted dying requests were cited at the hospice and in the specialty of haematology, but requests were less common in respiratory care. Dutch official statistics could be more sensitive to variations in the incidence of assisted deaths at the specialty level. The Dutch system of reporting an assisted death prompted some doctors to question its legality. Moreover, after the death, long waits for the Review Committees decisions on the validity of a case increased the impact. This influenced the ability of some doctors to consider new requests, contributing to equity and equality issues in assisted dying, which warrant further exploration

This chapter identifies the study's strengths and limitations. An acknowledged limitation is the recruitment of only one staff member with a conscientious objection to assisted dying. Amongst participating staff however, fluidity in support was also evident. Some doctors applied their right to objection to specific patient groups such as those with dementia. Others favoured limiting it to patients with incurable somatic illness. Several nurses cited the quality of medical care as a key requisite for their participation. Despite being broadly in support some staff expressed conflicted thoughts about assisted dying.

Assisted deaths were emotionally impactful for staff. Measures to reduce the impact included providing extra staff, allowing staff to go home after the death, and debriefing sessions. Staff from all professional groups 'never forgot' patients who succeeded in achieving an assisted death with places and events triggering their recall. Doctors and nurses however, differed in their view of the grieving process of family members. Doctors suggested that families were grateful and relieved, but nurses felt some families experienced difficulty with the manner of the death. This difference in perception may warrant further exploration and have implications for other bereavement research.

# Chapter Six: Conclusion

## 6.1 Introduction

This study sought to establish:

*What is the experience of assisted dying for Dutch healthcare staff working in a hospice or chronic disease care centre?*

Assisted dying is a sensitive, controversial and divisive topic, particularly in the field of palliative care. When subjected to a vote not all legislation is passed, but nonetheless, since commencing this study in 2013, assisted dying has been added to the statute books in the countries of Columbia and Canada, and the American States of California, Colorado and Washington D.C. During post-viva revision of this thesis permissive laws have been passed in the Australian State of Victoria, (Parliament of Victoria, 2018) and in Hawaii (Hawaii Governor, 2018), with 2019 commencement dates. Despite these developments the current empirical knowledge of the healthcare experience from the perspective of staff is limited (British Medical Association, 2016). To address this issue this study has focused on the experiences of doctors, nurses and therapists from the Netherlands which has the longest history of assisted dying in clinical practice.

This chapter starts with a short summary of the main findings under the overarching heading of 'never normal' (6.2) which includes the fluidity of objection towards assisted dying as cited by staff in this study. A personal reflective account follows which includes the impact the research has made on my own stance towards assisted dying (6.3). This is followed by four recommendations for practice based on the findings (6.4), and a final summary (6.5).

## **6.2 Assisted Deaths: 'Never normal'**

Dutch staff, with the longest experience of permissive legislation, suggested assisted deaths were 'never normal' and differed from their experiences of natural deaths. Expressed strongly by doctors, nurses and therapists during interviews, this was reinforced by staff at the Open Invitation Research Summary. This finding was distinct from conscientious objection as, at least superficially, the majority of staff recruited were broadly in favour of assisted dying. Deeper exploration of conscientious objection however, suggested fluidity with staff withdrawing their support for specific patient groups, or if the quality of medical care was in doubt. Some staff might have felt unable to be completely frank about their views, but the abnormal status attributed to such deaths appears to be at odds with the high level of public acceptance of assisted dying in the Netherlands (Cohen *et al*, 2014). It may however, serve a useful purpose, namely engendering extraordinary care which helped to

safeguard patients. Modern narratives surrounding assisted dying however, such as terminology linking assisted deaths to normal medical practice, may operate against this protective phenomenon by normalising assisted deaths.

Global variations in the configuration of palliative care services confound comparisons of its availability. Nonetheless staff valued its principles, using them to open up dialogue about dying, to resolve physical and existential issues, and to determine if the patient's suffering was unbearable. Notably, nurses were more active than previously reported, undertaking activities that may help to safeguard patients and, in chronic disease, delay assisted deaths. New insights have also been gained about the role of therapists. Many explored patient's expressions of interest in assisted dying, with activities organisers and creative therapists active in final requests. The study has also added clarity to the known role of social workers.

Assisted deaths are however, challenging for staff. Demands that were potentially illegal or impractical, such as those requested too late in the illness trajectory, frustrated doctors and nurses. For doctors, waiting for post-death confirmation that their actions had been lawful caused anxiety, especially after complex cases. The reporting procedures also caused some questioning of the legality of assisted dying in the Netherlands. Particularly challenging for doctors

was administering lethal drugs. The impact of the first such experience has already been reported (van Marwijk *et al*, 2007), but the impact of repeated administration warrants further investigation. For some doctors the challenges of assisted deaths influenced their ability to consider new requests, raising equity and equality issues, a neglected area of assisted dying which warrants consideration.

Assisted deaths had an emotional impact on all staff. More research is needed to explore this issue, but this study suggests such deaths may have an impact beyond that experienced after a natural death. This impact was recognised by staff who provided informal support to their colleagues and managers who reduced workloads, increased staffing ratios and instigated debriefing sessions. Not all staff however, found such activities helpful and for the socially isolated counselling or review by a psychologist may be helpful.

### **6.3 Final Reflections**

At the close of this study, my views have been refined as opposed to being dramatically altered, but studying a highly charged and sensitive topic has been challenging. Some friends and acquaintances have been shocked by my choice of topic, with their views on assisted dying difficult to predict on an individual basis. Friends with Christian beliefs were more open-minded than I expected.

Others however, had a firm moral objection. On several occasions people have incorrectly assumed my beliefs aligned with their own. Dealing with such issues whilst grappling with research at this level is difficult and I have avoided being drawn into debates or volunteering the focus of my study. Nonetheless, I'm comfortable with the topic which still holds my interest and the implementation of new legislation suggests it is still a contemporary issue.

Traveling, talking to clinicians and collaborating with other researchers in the same field, has been enjoyable and very stimulating. The process of learning has been fascinating and, when I held a University position, my new knowledge about research and its processes was invaluable. It was a joy to use this new knowledge to help students. Some assumptions however, have proved to be incorrect. Recruitment was swift, despite being flagged as a potential problem. The accounts recorded however, contained a bewildering mix of uplifting moments alongside the difficult. Analytical progress was slow and I was unable to make progress until my own stance towards assisted dying was resolved.

Assuming I would become either more in favour or more opposed I expected to resolve my views swiftly. In reality it was a long process resolved three years and three of months, in a 'eureka' moment, after the start of the study Making progress has been dependent on clarifying my personal stance. On the surface

my views have changed little. However, they are more nuanced. Currently, assisted dying in the United Kingdom is unlawful and the boundaries of what a Registered Nurse, such as myself, can discuss with patients are clearly defined (Royal College of Nursing, 2016). Whilst I would not act as an advocate for permissive legislation I would acknowledge that, for a small number of patients with a debilitating illness and poor prognosis, an assisted death might be seen as a desirable option. As a palliative care nurse, I do not want to suggest that a dying patient desires should not be met, but I recognise that there are wide-ranging practical consequences of permissive legislation.

The traditional concerns related to patient vulnerability appear to be unfounded, but other issues, such as recognising depression at the end of life, await resolution. Debates however, often lack an acknowledgement that such work is very challenging for staff. Where legislation is open-ended without a fixed likely prognosis the challenges may also be compounded. More recognition is needed that the challenges of such work require careful preparation, training and education and a level of psychological support that will sustain staff well-being. This has resource implications which should be acknowledged where assisted dying is being implemented or debated.

## 6.4 Recommendations for Practice

The following three recommendations (6.4.1 – 6.4.3) are based on the findings of this study. A summary of the finding is followed by recommendations which may be pertinent where assisted dying is already permitted, being implemented or considered.

### 6.4.1 Nurses and Decision-Making

Dutch nurses are active in assisted dying, assessing and resolving expressions of interest from patients, appraising physical and existential needs and supporting families and their colleagues. They also perform an important role in safeguarding patients.

**Recommendation:** The role of nurses willing to participate in assisted dying should be recognised in legislation. Nurses with care continuity with the patient should be formally included in the decision-making processes.

### 6.4.2 Palliative Care

The use of palliative care principles were cited as valuable to staff in their care of assisted dying patients. They aided assessment of legal criteria such as unbearable suffering, were utilised in exploring alternative options and in the

palliation of symptoms until death. The use of open dialogue, the alleviation of physical and existential distress, and the support of the family during the assessment process, death and into bereavement were all cited by staff as helpful.

**Recommendation:** A minimum level of palliative care training and education should be considered for all clinical staff who may receive assisted dying requests. Not all institutions or staff will be willing to participate in assisted deaths, but for those who do a higher level of palliative care education should be mandatory. A review of the strength, depth and accessibility of practitioners with palliative care knowledge should be considered prior to the implementation of permissive legislation.

### **6.4.3 The Provision of Psychological Support for Staff**

Assisted dying is emotionally challenging for staff especially at the time of death. Participating organisations should proactively implement measures to limit its impact, to support staff and maintain their well-being.

**Recommendations:** Participating staff should have access to psychological support during the assessment and care of assisted dying patients. Additional measures to promote staff well-being should include the reduction of workloads at the time of death and the provision of extra staff. Post-death structured debriefing and ongoing psychological support should be available.

## 6.5 Final Summary

A constructivist philosophical approach and qualitative methodology has provided a thought-provoking view of the multiple realities of assisted dying as expressed by Dutch staff. This has contributed some new insights to the existing knowledge. Some of the findings are specific to the Netherlands, but others may be more generic and may be pertinent to other jurisdictions.

The study suggests that implementing assisting dying can be emotionally demanding and requires high standards of care which benefit from the collaborative efforts of staff. Palliative care knowledge is helpful to staff and may help to safeguard patients, but the care of patients requesting and achieving an assisted death is challenging. Proactive psychological support and measures to ensure staff well-being should be considered essential.

Constructivism acknowledges that the constructed reality of staff is subjected to other influences and the views of staff in this study are subject to change. Qualitative inquiry also requires the interpretation of data as expressed by staff and other interpretations are possible. Therefore, the conclusions drawn here must be considered as this researcher's alone.

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## Appendices

## Appendix 1: Global Assisted Dying Legislation

Country, Province or State and relevant legislation	Permitted Activity	Due Care Criteria	Reporting and Review Procedures
<p><b>Switzerland</b> Swiss Penal Code (1942)</p>	<p>Physician-assisted suicide [self-administered] and non-physician assisted suicide</p> <p>Voluntary euthanasia is not recognised</p>	<p>Non-physician assisted suicide permitted providing the assister's motives are unselfish. Generally accessed via right-to-die organisations with their own internal protocols often including consultation with patient's own physician.</p> <p>Swiss law requires, if patient's primary condition is non-somatic, that a request is not the result of a treatable, e.g. a mental health, disorder.</p> <p>Zurich Canton: prescribing doctor, usually the patient's attending doctor, must meet the patient on two occasions (Fischer <i>et al</i>, 2008).</p>	<p>Assisted deaths are 'unnatural' and the police are notified usually by the right-to-die organisation. The police collate coroners' reports and witness statements.</p> <p>Deaths can be investigated by the Institute of Legal Medicine (Wagner, Müller, Maercker, 2012).</p> <p>Self-help organisations keep records with Dignitas (2017) publishing statistics on their website. Since 1998 1139 people from the United Kingdom have been aided to die by the clinic, an average of 67 per year. Other self-help organisation also provide a service to non-Swiss residents e.g. Exit International (Bosshard, 2012).</p>

<p><b>Oregon, USA</b> Death with Dignity Act 1994 [operational from 1997]: (Oregon Health Authority, 2017)</p>	<p>Physician-assisted suicide [self-administered]</p>	<p>Patient must be:</p> <ul style="list-style-type: none"> <li>• Aged 18 or over</li> <li>• An Oregon resident</li> <li>• Capable</li> <li>• Have a diagnosis of a terminal illness with prognosis of six months or less</li> </ul> <p>Also needed :</p> <ul style="list-style-type: none"> <li>• Two oral requests 15 days apart</li> <li>• A written request from patient signed by two independent witnesses</li> <li>• Prescribing and consulting physician must agree diagnosis and prognosis</li> <li>• Psychological assessment undertaken if necessary</li> </ul>	<p>To avoid prosecution the physician must submit to the Oregon Department of Human Services:</p> <ul style="list-style-type: none"> <li>• The patient’s written request</li> <li>• Consulting physician report and psychiatric evaluation to the State Public Health Division</li> </ul> <p>Also:</p> <ul style="list-style-type: none"> <li>• Pharmacists must be informed of the intended use of prescription and submit a notification form to State Public Health Division</li> <li>• Death certificates are sampled periodically with follow-up questionnaires to the attending doctor</li> <li>• Annual statistics publically available online</li> <li>• Non-compliance by doctors is reported to the Oregon Board of Medical Examiners</li> </ul>
<p><b>Netherlands</b> Termination of Life on Request and Assisted Suicide Act (2002) (TLRAS, 2002)</p>	<p>Euthanasia [by physician only] and physician-assisted suicide [self-administered]</p> <p>Includes minors 12 to 16 years old with parental consent, 17 to 18 years old if parents involved in decision-making</p>	<ul style="list-style-type: none"> <li>• Requests should be voluntary and persistent</li> <li>• Suffering unbearably without hope of improvement</li> <li>• Doctor and patient must agree</li> <li>• At least one independent doctor must be consulted and give a written opinion on the case</li> <li>• Patient must have mental competence and insight into the implications.</li> </ul>	<p>Death must not be certified as ‘natural causes’. Cases referred to local prosecutor for investigation who views the body and paperwork.</p> <p>Local prosecutor sends report to a Regional Euthanasia Review Committee [RERC] indicating if guidelines followed correctly. The RERC can ask for further investigation if necessary and annual national report produced (Review Committees, 2016b).</p>

<p><b>Belgium</b> Belgian Act on Euthanasia (2002) (Kidd, 2002)</p>	<p>Euthanasia [by physician only] including minors from 2014</p> <p>NB: Physician-assisted suicide is not included in the law because 'assisted suicide' is not explicitly illegal in Belgium (Nys, 2017 p.10). Some cases of physician-assisted suicide are reported to the Federal Control and Evaluation Commission (Griffiths <i>et al</i> 2008, p.311; Nys, 2017, p.10).</p>	<p>Patient must:</p> <ul style="list-style-type: none"> <li>• Have attained the age of majority or be an emancipated minor [no age limit since 2014]</li> <li>• Be legally competent and conscious at the moment of making the request</li> <li>• Have made a voluntary, well-considered and repeated request without any external pressure</li> <li>• Have a medically futile condition with constant and unbearable physical or mental suffering that cannot be alleviated resulting from a serious and incurable disorder caused by illness or accident</li> </ul>	<p>Notification by doctor to the Federal Control and Evaluation Commission within four working days obligatory. Case report considered by multidisciplinary Commission reporting back to the doctor within two months.</p> <p>Statistics collated biennially</p>
<p><b>Luxembourg</b> Euthanasia and Assisted Suicide (2009) (Ministry of Health, 2009)</p>	<p>Euthanasia and physician-assisted suicide [self-administered]</p>	<p>Patient must:</p> <ul style="list-style-type: none"> <li>• Be aged 18 or older or emancipated if between 16 and 18 with parental authorisation.</li> <li>• Make a request must be voluntary, well considered and not coerced</li> <li>• Capable and conscious at time of request</li> <li>• Medically futile incurable condition with constant unbearable suffering</li> <li>• Resident in country</li> </ul>	<p>Notification by doctor to the National Commission for Control and Assessment within eight days. Case report considered by multidisciplinary Commission reporting back to the doctor within two months.</p> <p>Statistics collated biennially</p>

<p><b>Washington State, USA</b>  Death with Dignity Act (2008)  (Washington State  Department of Health, 2017)</p>	<p>Physician-assisted  suicide [self-  administered]</p>	<p>Patient must:</p> <ul style="list-style-type: none"> <li>• Be aged 18 or older</li> <li>• Terminally ill with a likely prognosis no longer than six months</li> <li>• Be competent</li> <li>• Be a resident of the State</li> <li>• Have made a voluntary, non-coerced request</li> <li>• Be assessed by an independent consulting doctor</li> <li>• Supply a written request signed by two witnesses</li> </ul>	<p>Reporting procedures similar to those of Oregon, USA apply [see above].</p> <p>Annual statistics publically available online</p>
<p><b>Vermont, USA</b>  Patient Choice and Control at End of Life Act (Act 39) (2013)  (Vermont Department of Health, 2017)</p>	<p>Physician-assisted  suicide [self-  administered]</p>	<p>Patient must:</p> <ul style="list-style-type: none"> <li>• Be aged 18 or older</li> <li>• Be competent</li> <li>• Terminally ill and expected to die in six months</li> <li>• Have made a voluntary, non-coerced request</li> <li>• Be a resident of the State</li> <li>• Be assessed by an independent consulting doctor</li> <li>• Supply a written request signed two witnesses</li> </ul>	<p>Notification to State Health Department regarding writing of lethal prescription only</p> <p>Biennial statistical report available on the Vermont Government website  <a href="http://www.healthvermont.gov/systems/end-of-life-decisions/patient-choice-and-control-end-life">http://www.healthvermont.gov/systems/end-of-life-decisions/patient-choice-and-control-end-life</a></p>

<p><b>Quebec, Canada</b>  Bill 52: An Act Respecting End of Life Care (2013)  (Assemblée Nationale Québec, 2017)</p>	<p>Euthanasia [physician only]</p>	<p>Patient must :</p> <ul style="list-style-type: none"> <li>• Make a voluntary request</li> <li>• Be aged 18 or older</li> <li>• Have full capacity</li> <li>• Be insured to the level of the Health Insurance Act</li> <li>• Suffer from an incurable serious illness</li> <li>• Suffer an advance state of irreversible decline in capability</li> <li>• Suffer from constant and unbearable physical or psychological pain which can be relieved to a level the person deemed tolerable</li> <li>• Be assessed by a consulting physician</li> </ul>	<p>Cases are referred to the place of death's Council of Physicians, Dentists and Pharmacists who assess the quality of care provided. If the institution in which death occurred has no Council care will be reviewed by Head of Medical Services or the physician responsible for medical care.</p> <p>Within 10 days of death the physician must report the death to the multidisciplinary 'Commission on End of Life Care' who assess the compliance with regulations and provide annual statistics.</p>
<p><b>California, USA</b>  AB-15 End of Life Option Act (2015) (California Department of Public Health, 2017)</p>	<p>Physician-assisted suicide [self-administered]</p>	<p>Patient must:</p> <ul style="list-style-type: none"> <li>• Be aged 18 or older</li> <li>• Be terminally ill</li> <li>• Have made a voluntary, non-coerced request</li> <li>• Have made two oral requests 15 days apart</li> <li>• Be a resident of the State</li> <li>• Be assessed by an independent physician</li> <li>• Supply a written request signed two witnesses</li> </ul>	<p>Cases to be reported to the State Public Health Officer who reviews the documentation of a sample of cases annually and will provide an annual statistical report.</p>

<p><b>Columbia, South America</b> (Bill on Legislation of Euthanasia withdrawn in 2007, but procedural guidelines came into force on 20<sup>th</sup> April 2015)</p> <p>(Michlowski,2009; Dyer, White and Rada, 2015)</p>	<p>Euthanasia [physician only]</p>	<p>Patient must be:</p> <ul style="list-style-type: none"> <li>• Adult</li> <li>• Terminally ill with a non-degenerative disease</li> <li>• Informed by a doctor of their treatment options</li> <li>• If unconscious an audio, video or written advance directive may stand.</li> <li>• Case presented to a committee consisting of a medical expert, lawyer and mental health professional for consideration within 10 days. If granted doctors have a further 15 days in which to carry out the request.</li> </ul>	<p>Case reviewed by multidisciplinary committee for permission to proceed prior to the death.</p>
<p><b>Canada</b> Medical Assistance in Dying (2016) (Government of Canada, 2017)</p>	<p>Euthanasia [by physician or nurse practitioner] physician-assisted suicide [self-administered]</p>	<p>Patient must:</p> <ul style="list-style-type: none"> <li>• Be aged 18 or older</li> <li>• Be mentally competent</li> <li>• Have a grievous, irremediable medical condition</li> <li>• Have made a voluntary, non-coerced request</li> <li>• Be a Canadian resident</li> <li>• Be assessed by a second physician or nurse practitioner</li> <li>• Have a written request witnessed by two people</li> </ul>	<p>Consultation on monitoring and reporting regulations in 2017. Procedures commenced in 2018.</p> <p>Interim reports being published every six months available at: <a href="https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html#a7">https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html#a7</a></p>

<p><b>Colorado, USA</b> End of Life Care Options Act (2016) (Colorado Department of Public Health and Environment, 2017)</p>	<p>Physician-assisted suicide [self-administered]</p>	<p>Patient must</p> <ul style="list-style-type: none"> <li>• Be aged 18 or older</li> <li>• Be terminally ill with a likely prognosis of six months or less</li> <li>• Have made a voluntary, non- coerced request</li> <li>• Have mental capacity</li> <li>• Have made two oral requests 15 days apart</li> <li>• Be a resident of the State</li> <li>• Be assessed by an independent physician</li> </ul>	<p>Physicians report cases to the Department of Public Health and the Environment will annual review sampled cases.</p>
<p><b>Washington D.C, USA</b> Death with Dignity Act (2017) (District of Columbia, 2017)  (Cheh, 2015)</p>	<p>Physician-assisted suicide [self-administered]</p>	<p>Patient must</p> <ul style="list-style-type: none"> <li>• Be aged 18 or older</li> <li>• Be terminally ill with a likely prognosis of six months or less</li> <li>• Have made a voluntary, non-coerced request</li> <li>• Have mental capacity</li> <li>• Have made two oral requests 15 days apart</li> <li>• Be a resident of the District</li> <li>• Be assessed by an independent physician</li> <li>• Supply a written request signed by two witnesses</li> </ul>	<p>Physicians report cases to the District Department of Health State with an annual review of sampled cases.</p>

## Appendix 2: Dutch Legislation, Contested Cases and Surveys

Date	Legislation, Survey or Notable Cases (Griffiths, Bood and Weyers, 1998; Weyers, 2012)
1886	Dutch Penal Code Articles 293 and 294 prohibits the taking of life, inciting or assisting suicide.
1973	Dr T Postma [ <i>Postma Case</i> ] was prosecuted, receiving a one week prison sentence and a year of probation, for killing her mother who requested death following a stroke. Led to societal debate with the Dutch Association for Voluntary Euthanasia founded in same year (NVVE, 2017)
1982	Dr Schoonheim [ <i>Alkmaar Case</i> ] self-reported the euthanasia of a 95 year old patient with multiple illnesses who had repeatedly requested euthanasia. Led to recognition by the Supreme Court of <i>overmacht</i> , or 'necessity', in Dutch law.
1984	Royal Dutch Medical Association published position statement on euthanasia describing conditions where it may be justifiable.
1985	State Committee on Euthanasia Report defined euthanasia as voluntary and active.
1989	Government Commission of Inquiry into Medical Practice Concerning Euthanasia [ <i>Remmelink Commission</i> ] reviewing medical decisions at the end of life.
1990	National Survey led by Professor Paul Van der Maas [ <i>Remmelink Study</i> ] led to Ministry of Justice and Royal Dutch Medical Association agreeing to an official notification procedure.
1991	Dr Chabot, a psychiatrist, self-reported supplying lethal drugs to a 50 year old patient with depression and unresolved grief who had unsuccessfully attempted suicide. Although found guilty no punishment was levied. Dr Chabot was disciplined however, for not adhering to accepted standards of medical practice including not ensuring all treatment options had been exhausted.
1994	Amendment to the Burial Act notification procedures became law although euthanasia under Article 293 remains illegal. Doctors need to demonstrate 'necessity' and due care. Now, after the <i>Chabot Case</i> , 'necessity' could also be applied in cases of mental illness.
1995	Second National Survey highlighted small changes in practice in medical decisions at the end-of-life, but with no increase in assisted-dying cases with notification procedures working more effectively
1997	Government decided euthanasia was not to be legalised in the short-term, but multidisciplinary committees were established to encourage reporting.
2002	<i>Termination of Life on Request and Assisted Suicide Act</i> includes the current requirements for 'due care' and clarified reporting and monitoring procedures.

### **Appendix 3: Due Care Requirements (TLRAS, 2002)**

#### **The physician must:**

- hold the conviction that the request by the patient is voluntary, well considered and enduring.
- hold the conviction the patient's suffering is long lasting and unbearable.
- have informed the patient about the situation he/she is in and their prospects.
- ensure the patient holds the conviction there is no other reasonable solution for the situation he/she is in.
- have consulted with at least one other independent physician who has seen the patient and who has given a written opinion of the requirements of due care.
- have terminated the life or assisted in a suicide with due care.

#### **Reference**

TLRAS (2002) The Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act. Retrieved from <http://www.eutanasia.ws/documentos/Leyes/Internacional/Holanda%20Ley%20002.pdf>

### Appendix 4: Summary Table of Appraised Papers

Author (Year) Title Country Date of Data Collection Associated Papers Citation Tracked [CT]	Study Design	Sample Size and Sites	Key findings/ themes/ comments	Include/ Exclude  Appraisal Scores
<p>Ganzini <i>et al</i> (2000) Physicians' experiences with the Oregon Death with Dignity Act. <i>New England Journal of Medicine</i>, 342 (8): 557-563 USA</p> <p>1999: cases since Nov. 1997</p> <p>CT</p> <p>Associated papers: Ganzini <i>et al</i> (2001) <i>Journal of the American Medical Association</i>, 285 (18): 2363-2369.T</p>	<p>Quantitative: Self-completion, forced choice answer, postal questionnaire to assess doctors experiences of the Oregon Act</p>	<p>Total pop: 4053 licensed doctors</p> <p>Family practices and hospitals in Oregon</p>	<p>Response rate 65% [n=2649]. 165 cases, 29 patients received lethal medication with 39% of these taking it. Interventions: pain control [30%], control of other symptoms [30%], seeking a colleague's advice [28%], hospice referral [27%], mental health review [20%], antidepressants [18%], withdrawal of food and water [16%], palliative care [13%], social work [11%], chaplaincy [10%], or transfer to another doctor [9%]. Interventions altered patients mind set in 29. 5% of cases. 28 patients evaluated or received drugs for depression and anxiety, but only 3 changed their mind about an assisted death.</p> <p>Doctors' concerns: publicity, difficulty in gaining a second opinion or lethal drugs, lack of legal or patient knowledge, and an absence of dialogue with colleagues.</p>	<p><b>Include</b> <b>[++]</b></p> <p>[12/17]</p>

<p>Miller <i>et al</i> (2002) Take some time to look inside their hearts: Hospice social workers contemplate physician assisted suicide <i>Social Work in Health Care</i>, 35 (3): 53-63 USA 1994 to 1998</p>	<p>Qualitative: Semi-structured interviews with hospice social workers in Oregon. Data extracted from a larger ethnographic study which included 43 interviews. Constant comparative data analysis</p>	<p>8 social workers from 9 Oregon hospice programs</p>	<p>Themes: Hospice philosophy and social work's role Cardinal values and practice implications. Personal struggles</p>	<p><b>Exclude [-]:</b> <b>Data taken from a larger study during a legal transition zone. Unclear if social workers had experience. Data analysis procedure unclear.</b> [2/14]</p>
<p>Ganzini <i>et al</i> (2002) Experiences of Oregon nurses and social workers with hospice patients who request assistance with suicide. <i>New England Journal Medicine</i>, 347 (8): 582-588 USA 2001: cases since Nov. 1997  Associated papers: Miller <i>et al</i> (2004) <i>Palliative Medicine</i>, 18: 685: DOI 10.1991/0269216304pm961oa.</p>	<p>Quantitative: Self-completion, postal questionnaire to assess nurses and social workers' experiences of the Oregon Death with Dignity Act</p>	<p>545 hospice nurses and social workers [Total pop. in Oregon]  50 hospice programs in Oregon, 1 program in Washington State and 1 in Idaho caring for Oregon patients.</p>	<p>Total response rate 73% with nurses 71% and social workers 78%. 179 respondents cared for one or more assisted deaths. 26% opposed Oregon Death with Dignity Act, 59% in support and 14% neither opposed or in support. 55 of 82 patients who received lethal drugs had an assisted death, 17 died from other causes, outcome of 10 cases unclear. In 98% of cases nurses had discussed case with co-workers, at a multidisciplinary conference [77%] and with the patient's doctor [55%]. 61% of cases evaluated by a social worker and 49% of cases by a psychologist, psychiatrist or mental nurse practitioner. Outcome of 39% who requested, but did not receive lethal drugs included: doctor unwilling to prescribe [n=13], 12 died during legal process, 7 refused food and fluids with 4 not meeting criteria.</p>	<p><b>Include [+]</b> [9/17]</p>

<p>Dobscha, Heintz, Press and Ganzini (2004) Oregon physicians' responses to requests for assisted suicide: A qualitative study. <i>Journal of Palliative Medicine</i>, 7 (3): 451-461.</p> <p>USA</p> <p>2000</p> <p>Associated papers: Ganzini <i>et al</i>, (2003) <i>Journal of Palliative Medicine</i>, 6 (3): 381-390.</p>	<p>Qualitative: Grounded theory approach with data from semi-structured interviews exploring in more detail the experiences of doctors who had previously responded to a survey (Ganzini <i>et al</i>, 2000)</p>	<p>35 doctors from various specialties</p> <p>Oregon hospice programs</p>	<p>Themes: Before request: willingness to participate, but apprehensive Responding to requests: surprise, discomfort, avoidance of discussion for willing and unwilling doctors. Interpersonal factors: patients often liked by doctors for their determination and strong personalities. Requests persistent with a desire by the patient to maintain in control. Time and emotional commitment necessary with some doctors present at the death. Relief if patient died of natural causes. Some doctors had no regrets. Others regretted a lack of time which limited their opportunities to see the patient, but personal growth particularly in end-of-life care. Interaction with colleagues for some, but more often a lack support from colleagues or partners.</p>	<p><b>Include [++ ]</b></p> <p>[12/14]</p>
<p>Carlson, Simopolous, Goy, Jackson and Ganzini (2005) Oregon hospice chaplains' experiences with patients requesting physician-assisted suicide. <i>Journal of Palliative Medicine</i>, 6: 1160-1166</p> <p>USA</p> <p>2003</p>	<p>Quantitative: self-completion postal questionnaire to explore chaplains' experiences of the Oregon Death with Dignity Act</p>	<p>77 hospice chaplains [Total pop. in Oregon]</p> <p>Oregon hospice programs</p>	<p>Response rate 65% [n=50]. 40% supported the Oregon law, 42% opposed, 18% neither for nor against, 14% would oppose a patient's decision, but were willing to minister to a patient. No Oregon hospices have refused to admit an assist dying patient although institutional policies may limit staff participation.</p> <p>54% [n=27] had worked with an assisted dying patient, 36% [n=18] had ministered to an assisted dying patient. Most chaplains were comfortable discussing the topic. Chaplains did not feel they influenced the patient's decision as the patient had already made up their mind.</p>	<p><b>Include [+]</b></p> <p>[10/17]</p>

<p>van Marwijk, Haverkate, van Royen and The (2007) Impact of euthanasia on primary care physicians in the Netherlands. <i>Palliative Medicine</i>, 21:609-614 The Netherlands 2003 CT</p>	<p>Qualitative: Focus groups homogenised by gender, age and level of assisted dying experience to assess the emotional impact of assisted dying on doctors</p>	<p>Primary care doctors [n=22] approached directly from a local register or via snowball sampling.</p>	<p>Themes: Emotional experience: impact of first occasion, tension/loss' relief, relationship with patient and loneliness. Coping: Feeling 'put upon', taking time and sharing. Role of the doctor: dilemmas and pressures. Includes activities to aid doctors' well-being.</p>	<p><b>Include [-]: but methodological issues including lost data</b> [5/14]</p>
<p>Norwood (2007) Nothing more to do: euthanasia, general practice and end-of-life discourses in the Netherlands. <i>Medical Anthropology</i>, 26: 139-174 The Netherlands 1999 and 2001 CT</p>	<p>Qualitative: 15 month ethnographical study to explore the practice of euthanasia applying a discourse analysis to data</p>	<p>Observation of 10 doctors, patients and families in primary care including 25 end-of-life care consultations</p>	<p>Themes: Five common stages in 'euthanasia talk': 1. Initial euthanasia request 2. Written declaration 3. Second opinion appointment 4. Scheduling euthanasia 5. Euthanasia death</p>	<p><b>Include [++ ]</b> [14/14]</p>
<p>Borgsteede <i>et al</i> (2007) Communication about euthanasia in general practice: opinions and experiences of patients and their general practitioners. <i>Patient Education and Counseling</i>, 66: 156-161 The Netherlands 2002 and 2003 CT</p>	<p>Qualitative: Semi-structured interviews with family doctors and patients to investigate whether patients and their family doctors talk about euthanasia and, if so, how they talk about it (a secondary aim of the study)</p>	<p>20 doctors and 30 patients recruited by the participating doctors. Purposive and snowball sampling  Primary care sites in various districts of the Netherlands</p>	<p>Themes: Patients' characteristics: cancer and non-cancer diseases, but nearly half did not discuss assisted dying. Discussion on future decision-making more common than dialogue about assisted dying. Clarifying and fine-tuning: the patient and doctors must agree it is the best option. Initiative and timing: Doctors left it to patients to initiate dialogue, but were sensitive to cues. Some religious patients did want to discuss assisted dying. More end-of-life training focusing on communication of death, dying and assisted dying recommended.</p>	<p><b>Include [+]</b> [7/14]</p>

<p>Georges, The, Onwuteaka-Philipsen and van der Wal (2008) Dealing with requests for euthanasia: a qualitative study investigating the experience of general practitioners. <i>Journal of Medical Ethics</i>, 34:150-155</p> <p>The Netherlands</p> <p>2002 and 2003</p> <p>CT</p>	<p>Qualitative: In-depth interviews to assess the experience of general practitioners dealing with requests for euthanasia. Data coded using constant comparative method</p>	<p>25 doctors with 'restrictive views' on assisted dying as reported in a previous nationwide survey. Additional criteria included age, gender and geographical location, but the specifics are not reported</p>	<p>Themes:</p> <p>Avoidance of assisted dying as seen as a heavy responsibility. Alternatives included sedation, increasing opioid doses, waiting for death, enhancing quality of life by good palliative care and active caring. Approach to requests influenced by personal views such as religion. Even if wishing to avoid assisted dying doctors strove to be open and to consider requests carefully. There was an awareness of being able to cope with personal consequences if an assisted death took place.</p>	<p><b>Include [-]</b></p> <p>[6/14]</p>
<p>van Bruchem-van de Scheur <i>et al</i> (2008) The role of nurses in euthanasia and physician-assisted suicide in the Netherlands. <i>Journal of Medical Ethics</i>, 34: 254-258.</p> <p>The Netherlands</p> <p>Cases relate to 2001, 2002 and 2003</p> <p>CT</p>	<p>Quantitative: National self-completed questionnaire to assess the role of Dutch nurses. Anonymity for organisations and respondents guaranteed</p>	<p>1509 nurses recruited by designated contact person at the site</p> <p>73 hospitals, 55 home care providers and 63 nursing homes</p>	<p>Response rate 78.1.</p> <p>Some requests known prior to the nurse's involvement (11%), but in 37% of cases a nurse the first person to hear request.</p> <p>Decision-making: involvement 81.3% for nursing home nurses, 78.6% in hospitals, 41.2% in home care. 88.6% agreed with doctor's decision to grant request, 10.8% disagreed. Disagreements due to conscientious objection, the patient being too well or their suffering not being hopeless. If request refused 60.1 % agreed with decision, 37.2% had doubts because unbearable suffering did exist.</p> <p>Administering lethal medication: nurses were present to support the patient [85.6%] and support relatives [92.1%]. In 2.4% of cases nurses gave lethal drugs with the doctor e.g. assisting with an infusion device, in 0.5% of cases administered by a nurse anaesthetist [n=1], via a gastrostomy drip-feed [n=1], or nurse gave drugs in presence of a nurse colleague [n=2] despite such actions being illegal</p>	<p><b>Include [++]</b></p> <p>[12/17]</p>

<p>Dierckx de Casterlé, Denier, De Bal and Gastmans (2010) Nursing care for patients requesting euthanasia in general hospitals in Flanders, Belgium. <i>Journal of Advanced Nursing</i>, 2410-2420 Belgium 2005 and 2006 Associated papers: Denier <i>et al</i> (2010). <i>Journal of Clinical Nursing</i>, 19: 3372-3380. Denier <i>et al</i> (2010) <i>Medicine, Healthcare and Philosophy</i>, 13: 41-48.</p>	<p>Qualitative: In-depth interviews analysed using a Grounded Theory approach to explore the nursing care for patients requesting euthanasia in general hospitals in Flanders, Belgium</p>	<p>Theoretical sampling resulting in 18 nurses participating  Nine hospitals in Flanders</p>	<p>Seven stages of the nursing care process 1. The period preceding requests 2. Confrontation with the request 3. Decision-making 4. Preceding the death 5. Carrying out the death 6. Immediate aftercare 7. Later aftercare</p>	<p><b>Include [++]</b>  [12/14]</p>
<p>Inghelbrecht, Bilsen, Mortier and Deliens (2010) The role of nurses in physician-assisted deaths in Belgium. <i>Canadian Medical Association Journal</i>, 182 (9): 905-910.  Belgium  2007 and 2008</p>	<p>Quantitative: Self-completion postal questionnaire to assess the role of nurses in assisted dying under the Law on Euthanasia (2002) of Belgium</p>	<p>1678 nurses, all respondents to a previous attitudinal survey and chosen for their experience of decisions with a possible life shortening effect  Hospital, care home or home care</p>	<p>Response rate: 76%. 120 nurses reported a life-shortening decision with an explicit request [later defined as euthanasia] Decision-making: nurses involved in assisted dying decision-making in 25% in home care, but less often in care homes (16%). Administering medication: preparing drugs 40% of nurses involved, 34% nurses present when drugs delivered, 31% supporting the patient, relatives, doctor or nursing colleagues. Nurses administered drugs in 14 (12%) of cases on the doctor's orders with drugs being: a neuromuscular relaxant (n=4), barbiturates (n=1) and opioids (n=9).</p>	<p><b>Include [+]: but key terms not defined until after data collection so the aim of the survey may not have been clear to respondents.</b>  [11/17]</p>

<p>Norton and Miller (2012) What their terms of living and dying might be: hospice social workers discuss Oregon's Death with Dignity Act. <i>Journal of Social Work in End of Life and Palliative Care</i>, 8 (3):249-264.</p> <p>Date: NR : 2011 implied</p> <p>Oregon, USA</p>	<p>Qualitative: Single focus group with thematic analysis applied to the data to explore the experiences of social workers in Oregon hospices.</p>	<p>Nine hospice social workers working in organisation providing hospice care in urban and rural Oregon.</p>	<p>Themes:  Values surrounding the Oregon Death with Dignity Act  Policy surrounding the Oregon Death with Dignity Act  Role of the hospice social worker  Insights of interest:  Assisted dying procedure complicated and demanding for patients. Social workers refer patients to advocacy organisations to speed up the process  Family and friends have an impact of the patient's choices and some colleagues avoided the topic with patients.  Policy of organisation can impact on outcomes, but some social workers 'got round' this.  Lack of clarity in social workers role.</p>	<p><b>Include [-]: few studies related to therapists and it includes some new insights.</b></p> <p>[5/14]</p>
<p>Voorhees, Rietjens, van der Heide and Drickamer (2014) Discussing physician-assisted dying: Physicians experiences in the United States and the Netherlands. <i>Gerontologist</i>, 54 (5): 808-817</p> <p>The Netherlands and USA</p> <p>2007 and 2008</p> <p>CT</p>	<p>Qualitative: Semi-structured interviews and thematic analysis comparing the experiences of doctors discussing assisted dying in jurisdictions where it is legal (Oregon and the Netherlands) and illegal (North-Eastern States, USA)</p>	<p>18 doctors from the Netherlands and 18 from America including 5 from Oregon and 13 from North-Eastern States. Purposive and snowball sampling by email, telephone and word of mouth.</p> <p>The Netherlands, Oregon and North-eastern USA</p>	<p>Themes:  Assisted dying discussions with patients: a range of experiences, more likely to be initiated by doctors if legal with content led by terms of legislation.  Doctor-patient relationship affected by dialogue: strengthening the relationship, but refusal could cause riffs and disappointment.  Doctors' emotions: intensive emotions both negative and positive.  Discussions with others: intensive in the Netherlands and empowering in Oregon, but lacking if assisted dying not legal.  Influencing dialogue: legality, perception of doctors' roles, patients' rights and autonomy, and religion.</p>	<p><b>Include [+]</b></p> <p>[9/14]</p>

<p>Snijdewind, van Tol, Onwuteaka-Philipsen and Willems (2014). Complexities in euthanasia or physician-assisted suicide as perceived by Dutch physicians and patients' relatives <i>Journal of Pain and Symptom</i>. 48 (6): 1125-1134</p> <p>The Netherlands</p> <p>2011 and 2012</p> <p>CT</p>	<p>Qualitative: In-depth interviews with doctors, and relatives of assisted dying patients with inductive coding initially and application of a coding schema to later interviews</p>	<p>28 doctors from the Support and Consultation service and a Dutch national, study, and 26 relatives via a nationwide survey and a Right-to-Die magazine</p>	<p>Theme: Relational Complexities:  Growth: assisted dying a process of growth. Family play an important role. An absence of growth can request in rejected requests.  Miscommunication: misunderstanding common, doctors can feel pressured with application of moral pressure by patients.  Invisible suffering: doctors and relatives not always aware of the patients suffering especially if psychological.  Occurrence of unexpected situations: e.g. rapid physical decline, a lack of time for assessment, and the need to transfer patient. These led to assisted requests not being carried out</p>	<p><b>Include [+]</b></p> <p>[9/14]</p>
<p>Bilsen, Robijn, Chambaere, Cohen and Deliens (2014) Nurses' involvement in physician-assisted dying under the euthanasia law in Belgium. <i>International Journal of Nursing Studies</i>, 51:1696-1697</p> <p>Flanders, Belgium</p> <p>2007</p> <p>Previous papers:  Bilsen <i>et al</i>, (2009) Medical end-of-life practices under the euthanasia law in Belgium. <i>New England Journal of Medicine</i>, 361, (11), 119-1121.</p>	<p>Quantitative: Self completion by doctors to assess nurses' involvement in assisted deaths under the Law on Euthanasia (2002) in Belgium to assess nurses' involvement in assisted dying decision-making and drug administration</p>	<p>Random sample of doctors [N=6927] taken from a death certification study</p>	<p>Response rate 58.4%.  Incidence of assisted dying 0.2% [nursing homes], 1.7% [hospitals], 4.2% [at home].  Decision-making: Doctors discussed decision with nurses in 100% of cases [nursing homes], 56.6% [hospital] and 44.4% [home].  Administration of drugs by nurses: 0% [nursing homes], 43.4% [hospitals] and 13.5% [home] cases. A higher percentage of drug administration is noted in ending of life without the patient's request, in 25% [nursing homes], 61.4% [hospitals] and 27.3% [home] of cases but the drugs were "nearly exclusively opioids" (p.1696, para.3). Comparisons made to a similar earlier survey Bilsen <i>et al</i>, (2009). This suggested that involvement of nurses in decision-making had grown with a fall in drug administration by nurses.</p>	<p><b>Exclude [-]: retrospective proxy reporting of nurses actions by doctors.</b></p> <p>[2/17]</p>

<p>Francke, Albers, Bilsen, de Veer, Onwuteaka-Philipsen (2016) Nursing staff and euthanasia in the Netherlands. A nation-wide survey on attitudes and involvement in decision-making and the performance of euthanasia. <i>Patient Education and Counseling</i> 99: 783-789.</p> <p>The Netherlands</p> <p>2011</p>	<p>Quantitative: Self completion questionnaires for Registered Nurses and certified nursing assistants</p>	<p>Sample of nurses on a research database [n=903] of staff willing to complete surveys on nursing topics.</p>	<p>Response rate 65%.          Involvement in decision-making: 24% involved by doctors, 12% had heard a request, but were not involved. First person to hear a request: 38%. 35 % had Informed a doctor of a request, 3% had refused to participate in decision-making.          Involvement in performance: 7% had been present, 10% present to support relatives, 3% had prepared lethal drugs or an infusion, 2% had turned on a drip value and 1% had administered lethal drugs.</p>	<p><b>Include [++]</b></p> <p>[9/17]</p>
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## Appendix 5: Search Terms

Search Strategy	Search Terms
<p>Electronic databases: CINAHL, MEDLINE, PsycINFO, AMED and Web of Science</p> <p>Initial hits: 254 Field: Abstract [except Web of Science: Title]</p>	<p>Euthanasia OR "Assisted Dying" OR "Assisted Suicide" OR "Physician-Assisted Suicide" AND Experienc* OR Impact* OR Psycholog* AND Therap* OR Doctor* OR Nurs* OR "Profession* Allied to Medicine" OR Healthcare Profession* OR "Social Work*" OR Physio*, "Speech Therap*" OR "Activities Organiser*"</p>
<p>EMBASE Initial hits: 19</p>	<p>"Assisting Dying" OR Euthanasia AND Experience</p>
<p>WorldCat: Initial hits: 13</p>	<p>"Assisted Dying" [Title] AND "Experience" [key word] "Euthanasia" [Title] AND "Experience" [key word]</p>
<p>EThOs Initial hits: 26</p>	<p>"Assisted Dying" "Euthanasia"</p>

## Appendix 6: Initial Invitation



Dear Sir/Madam,

I am writing to invite you to participate in a research study taking place at Name Withheld. My name is Debbie Lewis. I am a nurse with experience in Palliative Care currently working at the Birmingham City University in the West Midlands, England.

As part of a PhD in Palliative Care, supervised by Lancaster University, I am conducting a research study exploring the experience of being involved with patients who choose euthanasia. I am interested in gaining a better understanding of the practical and emotional experiences of doctors, nurses and other professional staff exploring the issues you face in individual interviews. These private interviews will take place during normal working hours at your place of work in quiet room away from the main clinical area.

You are invited to participate because you may have experience in this area of patient care. Your information may be helpful for your colleagues in the Netherlands, and other countries where euthanasia is not yet legal, but where it may be permitted in the future. Your organisation has agreed to participate in this research study. The information you provide will be computer coded and anonymised so it will remain confidential.

If you wish to participate please make contact and I will send you an information pack containing additional information including a Participant Information Sheet and a Consent Form. Your participation will be valuable and is entirely voluntary.

For further information please contact me:

Debbie Lewis Senior Lecturer

Work Address: Birmingham City University, Bevan 224, Westbourne Road, Edgbaston, Birmingham. B15 3TN.

Email: [deborah.lewis@bcu.ac.uk](mailto:deborah.lewis@bcu.ac.uk)

Tel: 44 121 331 7160

Skype: debbielewisbcu

## Appendix 7: Letter of Invitation and Participant Information Sheet

Mrs Debbie Lewis  
Researcher/PhD Student  
Lancaster University  
Work Address  
Birmingham City University  
Bevan 224, Westbourne Road  
Edgbaston, Birmingham. B15 3TN.

Dear Sir/Madam,

Thank you for your interest in this project.

This research is being carried out to fulfil the requirements of a PhD in Palliative Care being conducted under the supervision of Lancaster University in Lancashire, England. This study has been reviewed by the Faculty of Health and Medicine Research Committee, and approved by the University Research Ethics Committee at Lancaster University. It has also been seen by the Maastricht University's Medical Research Ethics Committee in the Netherlands and approved by the management of your organisation.

I hope to obtain information to improve our knowledge of the experience of euthanasia by healthcare professionals working in clinical practice. I am interested in gaining a better understanding of the practical and emotional experiences of doctors, nurses and other professional staff and will be using individual interviews to explore your experiences and issues.

Every effort will be made to ensure your comments will be confidential. The information you provide will be computer coded and anonymised so your insights remain confidential from the start of the study and including any future publications. If there is any possibility of you being identified by any comments you have made this will be discussed with you prior to their use. You will find additional information in the enclosed Participant Information Sheet with a Consent Form. Your participation is voluntary.

For further information please contact me at:

Email: [deborah.lewis@bcu.ac.uk](mailto:deborah.lewis@bcu.ac.uk)

Tel: 44 121 331 7160.

Skype: debbielewisbcu

Yours sincerely

Debbie Lewis, Senior Lecturer MSc, RGN, DN Cert

## **Participant Information Sheet**

### **Euthanasia in the Netherlands: The experience of healthcare professionals in a hospice and chronic disease care centre.**

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

#### **What is the study about?**

The purpose of this study is to improve our knowledge of the experiences of healthcare professionals and euthanasia in the Netherlands. The study will use information gathered in individual interviews to gain insight into the experience of healthcare professionals who participate, or abstain, from euthanasia in practice. This information will help me, and the wider society, to learn from your experiences.

#### **Why have I been approached?**

You have been approached because you have had experience of caring for patients who have chosen the clinical option of euthanasia. If you have cared for such patients, even if you are conscientious objector, this will help us to gain valuable insights into this complex area of care. If too many staff wish to participate equal numbers of doctors, nurses and therapists will be recruited in order of their expression of interest.

#### **Do I have to take part?**

No. It's completely up to you to decide whether or not you take part. Your participation is voluntary and you can withdraw from the project during the research process if you wish without giving any reasons.

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

If you decide you would like to take part, you will have an individual interview with me. This will give you the opportunity to discuss your experiences in confidence. Interviews will take approximately 60 to 90 minutes in total. You can withdraw if you wish at any time during the interview and you can withdraw any interview recordings up to two weeks after the interview.

### **Will my data be confidential?**

Every effort will be made to ensure your comments will be confidential. Data management will be my responsibility and will be the property of Lancaster University. With your permission data will be audio recorded during the interview and will be stored securely. You can decline audio recording and I will make hand written notes instead.

Audio recordings will be deleted from the recording device after being downloaded on a computer. The files on the computer will be encrypted (that is no-one other than me, the researcher, will be able to access them) and the computer itself will be password protected.

- All personal data relating to you will be stored separately from transcripts on a mobile storage device that is encrypted and password protected.
- Your transcribed interview will be made anonymous by removing any identifying information including your name. All hard copies of transcripts and any additional notes will be kept in a locked cabinet when not in use.
- Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. If there is any possibility of you being identified by any comments you have made perhaps, for example if you are a conscientious objector to euthanasia, this will be discussed with you prior to using your comments.
- All data held on computer will be destroyed after five years from the end of the study using software to ensure it cannot be retrieved from hard drives. Mobile storage devices will be physically destroyed. If data is deemed to be of historical interest it may be archived in the United Kingdom if a suitable repository is available at the time. Confidentiality regulations will still be applied.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, are at significant risk of harm, I will have to break confidentiality and speak to, in the first instance, my supervisors about this and take appropriate action if necessary.

### **What will happen to the results?**

The results will be summarised and reported in a PhD thesis some of which may be submitted for publication in an academic or professional journal if they are likely to be helpful or of interest to other healthcare professionals.

### **Are there any risks?**

There should be no risks anticipated with participating in this study. It is, however, a sensitive topic area and if you wish to discuss your involvement further please contact me. If you become distressed during an interview the interview will stop and you will be invited to rearrange the interview only if you wish to do so. If you experience any further distress following participation you are encouraged to inform me and to access the resources provided at the end of this sheet.

### **Are there any benefits to taking part?**

Although you may find participating interesting, there are no direct benefits in taking part although you may find it helpful to have the opportunity to discuss your experiences.

### **Who has reviewed the project?**

This study has been reviewed by the Lancaster University's Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee. It has also been seen by the Maastricht University's Medical Ethics Committee (METC 12-5-043). Your organisation has agreed to participate in the research.

### **Where can I obtain further information about the study if I need it?**

If you have any questions about the study, please contact the researcher:

Mrs Debbie Lewis, Researcher/PhD Student, Lancaster University

Work Address: Birmingham City University, Bevan 224, Westbourne Road, Edgbaston, Birmingham. B15 3TN.

Email: [deborah.lewis@bcu.ac.uk](mailto:deborah.lewis@bcu.ac.uk). Or Tel: 44 121 331 7160. Skype: debbielewisbcu

### **Complaints:**

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to me you can contact:

Professor Sue Cartwright  
Head of Division of Health Research  
Email: [s.cartwright@lancaster.ac.uk](mailto:s.cartwright@lancaster.ac.uk)  
Tel: (01524) 592430  
C04 Furness College  
Lancaster University  
Lancaster  
LA1 4YG

Professor Paul Bates  
Chair in Biomedicine  
Email: [p.bates@lancaster.ac.uk](mailto:p.bates@lancaster.ac.uk)  
Tel: (01524) 593718  
C41, Bowland North  
Lancaster University  
Lancaster  
LA1 4YQ

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, you will be able to talk to the Confidential Advisor provided for all employees in the Netherlands, accessible via your organisation, to obtain counselling and psychological support if necessary.

## Appendix 8: Biographies of Staff and their Assisted Dying Stance

Participant No/Care Setting	Professional Group (male or female)	Pseudonym	Clinical and Assisted Dying Experience	Stance on Assisted Dying
1. Hospice	Therapist (f)	Tess	A hospice 'Activities Organiser' who also held nursing qualifications with experience of several assisted deaths.	<i>"Good that it is possible if life is bad and hopeless."</i>
2. Hospice	Doctor (f)	Cornelia	A hospice doctor working in palliative medicine. She referred patients requesting assisted dying to their family doctor.	<i>"I study to be a doctor to help patients not kill them."</i>
3. Hospice	Nurse (f)	Maud	A nurse with twenty-five years of experience, sixteen at the hospice and eight or nine assisted deaths.	<i>"Good that the option of assisted dying is there."</i>
4. Hospice	Nurse Manager (f)	Gwen	A nurse with thirty-three years of nursing experience, fifteen years at the hospice and five or six assisted deaths.	<i>"Yes [in principle], but every case is a new one." [needs careful assessment]</i>
5. Hospice	Psychiatric Nurse (m)	Abe	A nurse with twenty-two years of experience recently employed by the hospice, but previous experience of four assisted deaths.	<i>"You can be sick for long years and now and then then someone says 'No, it is enough', it's enough."</i>
6. CDCC	Nurse (f)	Famke	A nurse with ten years of respiratory experience and of one assisted death	<i>"I think euthanasia is a good thing."</i>

7. CDCC	Nurse (f)	Britt	A nurse for thirty-five years she had worked on the unit for seventeen years. She remembers two cases of assisted dying well.	Happy with current law, but emphasised the good medical care on the unit.
8. CDCC	Doctor (f)	Lara	A doctor on a training rotation who had experience of an assisted dying case in primary care.	<i>"More in favour of euthanasia" [than conscientious objection].</i>
9. CDCC	Therapist (f)	Jade	A social worker with seventeen years of experience and who worked with two assisted dying patients and their families.	Agrees with assisted dying if there is <i>"no way to get better, to feel better."</i>
10. CDCC	Therapist (f)	Fay	A creative therapist who had contact with two assisted dying patients working therapeutically with one.	<i>"Yes, I think that if are that ill and only have one wish it's OK."</i>
11. CDCC	Doctor (f)	Ilse	Elderly and palliative care doctor who had performed three assisted deaths. Cited by others doctors as a source of support and advice.	Assisted dying for patients with dementia <i>"a step to far"</i> declines to assess these patients.
12. CDCC	Volunteer and retired nurse (f)	Anouk	A retired nurse who supported staff at the time of an assisted death. She had worked at facilities that supported it, but also at a hospice which did not.	<i>"I'm certainly not against it."</i>
13. CDCC	Doctor (m)	Ruben	A respiratory physician with experience of two assisted deaths and approximately five requests in total.	<i>"Yes"</i> when asked if in favour of assisted dying.
14. CDCC	Nurse (f)	Emma	A young nurse working on a rehabilitation ward for respiratory patients with experience of one assisted death.	<i>"Yes"</i> when asked if in favour of assisted dying.

15. CDCC	Therapist (m)	Noah	A physiotherapist working predominately with patients with dementia. His father-in-law had an assisted death at home.	In favour, but saw <i>"taking care of the process"</i> as important now and in the future.
16. CDCC	Doctor (f)	Sophie	A doctor specialising in Internal Medicine, but with exposure to assisted dying patients in haematology whilst on a training rotation.	<i>"For some patients I think it is a good option."</i>
17. CDCC	Nurse (f)	Zoe	A senior nurse working on the ward and in triage with experience of one assisted death but many more requests.	<i>"I think it is good to talk about it. If is necessary to do it, I don't know."</i>
18. CDCC	Doctor (m)	Liam	A respiratory physician who had achieved seniority at a young age. Closely involved with one assisted death.	Not expressed directly, but stated being <i>"happy"</i> to discuss it with patients and colleagues.
19. CDCC	Therapist (f)	Mila	A speech and language therapist who had worked with two patients who chose an assisted death.	In agreement with current Dutch law, but considered it in dementia as <i>"difficult and different."</i>
20. CDCC	Nurse (f)	Eva	An experienced ward nurse with involvement in two cases, knowledge of other cases and several requests.	<i>"It is good there is the opportunity for a choice."</i>
21. CDCC	Doctor (m)	Tim	An elderly care physician who had previously worked as a family for eight years. Experience of four cases and approximately 40 requests.	Agreed with assisting dying, but did not view as legal because of the Dutch reporting procedures.

## **Appendix 9: Interview Questioning Guide**

### **Initial Activities: interviewer**

- Reiteration of research nature and purpose.
- Reaffirm confidentiality boundaries, seek permission to record and stress flexibility.
- Exploration of the role of participant, length of time in role, participant's connection to the chronic disease care centre or hospice

### **During the Interview**

- Invite participant to discuss their experiences of euthanasia allowing participants time to reply. Possible prompts:
  - What sort of cases have they been involved in? Euthanasia and/or physician-assisted dying?
  - Or do they abstain from cases? [See alternative topic guide below]
  - Amount of experience. How many patients? Over how long? What type of patients? E.g. what conditions and in what age groups? How were they involved?
  - How long was their relationship with the patient?
- Any particularly difficult areas to address?
- How do they feel after the patient had died? Has the participant's attitude to assisted dying altered over time? Is the current legislative framework in the Netherlands adequate?
- Any emotional challenges? If yes, what are these? What, if any, supportive networks are in place? Self-support mechanisms? Any extra support/preparation needed?

### **Alternative topic guide if abstaining from assisted dying**

Is the staff member a conscientious objector?

- If yes, on what grounds and why? Have their views changed over time?
- How is this handled by the individual? Is there an emotional impact?
- What practical issues does it raise? Is it difficult to withdraw from the care of such patients? Would staff member still be involved in the care of the family?
- Do they have any thoughts about the current legislative framework in the Netherlands?

### **Ending the Interview**

- Is there anything to add? Other issues of importance?
- Switch off recorder, say thank you and check out if the participant is feeling OK. If distressed offer support. Reaffirm sources of psychological support.



<p>I: Yes. OK. Yes.</p> <p>P: And when she came the second time she was very closed also to me and on certain days she said to me 'It's hard, life is hard and I don't want this anymore' but she didn't not talk about life ending or..... #00:01:56-8#</p> <p>I: Anything like that? OK. #00:01:57-7#</p> <p>P: But she wanted on that time a conversation with the doctor [Doctor Named] and me and the whole family. It was a busy meeting. #00:02:14-2#</p> <p>I: //Um, um. // #00:02:12-7#</p> <p>P: And on that time she talked for the first time about euthanasia. #00:02:20-1#</p> <p>I: What condition did she have? What illness did she have? #00:02:23-0#</p> <p>P: She had COPD [<i>Chronic Obstructive Airways Disease</i>] and lung emphysema. #00:02:29-4#</p> <p>I: //um, um. // #00:02:30-1#</p> <p>P: Yes. She was young and she had to let everything loose. She was always a busy women and she err... manage her things by herself and on one occasion she didn't ...yes...do that anymore so the simplest things did not go well. #00:03:03-0#</p>	<p>Clinical condition: struggling with symptoms/fatigue</p> <p>Multidisciplinary review</p> <p>The request was a surprise to the nurse</p> <p>Clinical condition of patient</p> <p>Patient characteristics: patient likes to be in control</p>
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<p>I: //Um, um. // #00:03:06-2#</p> <p>P: Not to her children, not to her Mother and that part of life not to assist us and her self-respect was a little less [<i>patient had lost her role</i>]. She can't go to the toilet; she was [indistinct word - incontinent?]. #00:03:26-1#</p> <p>I: Life had got quite difficult for her? #00:03:26-7#</p> <p>P: //Yes.// Yes. #00:03:23-1#</p> <p>I: In your experience do a lot of patients want to talk to you about euthanasia? Or...#00:03:28-8#</p> <p>P: [Pauses and signs whilst thinking]. Not as this woman [<i>did</i>]. #00:03:38-3#</p> <p>I: //Um. // #00:03:38-3#</p> <p>P: There are people who often say.... '<b>Life is hard</b>'. #00:03:41-1#</p> <p>I: //Um.// #00:03:41-1#</p> <p>P: But that feeling is going away when something positive happens. #00:03:51-0#</p> <p>I: Um, um. #00:03:51-0#</p> <p>P: Err....but with this lady that feeling stayed, she made that decision</p>	<p>Patient characteristics: Fear of being a burden</p> <p>Patients not always serious, but this one was</p> <p>Psychological status: Fluctuating: 'Good and bad days'</p>
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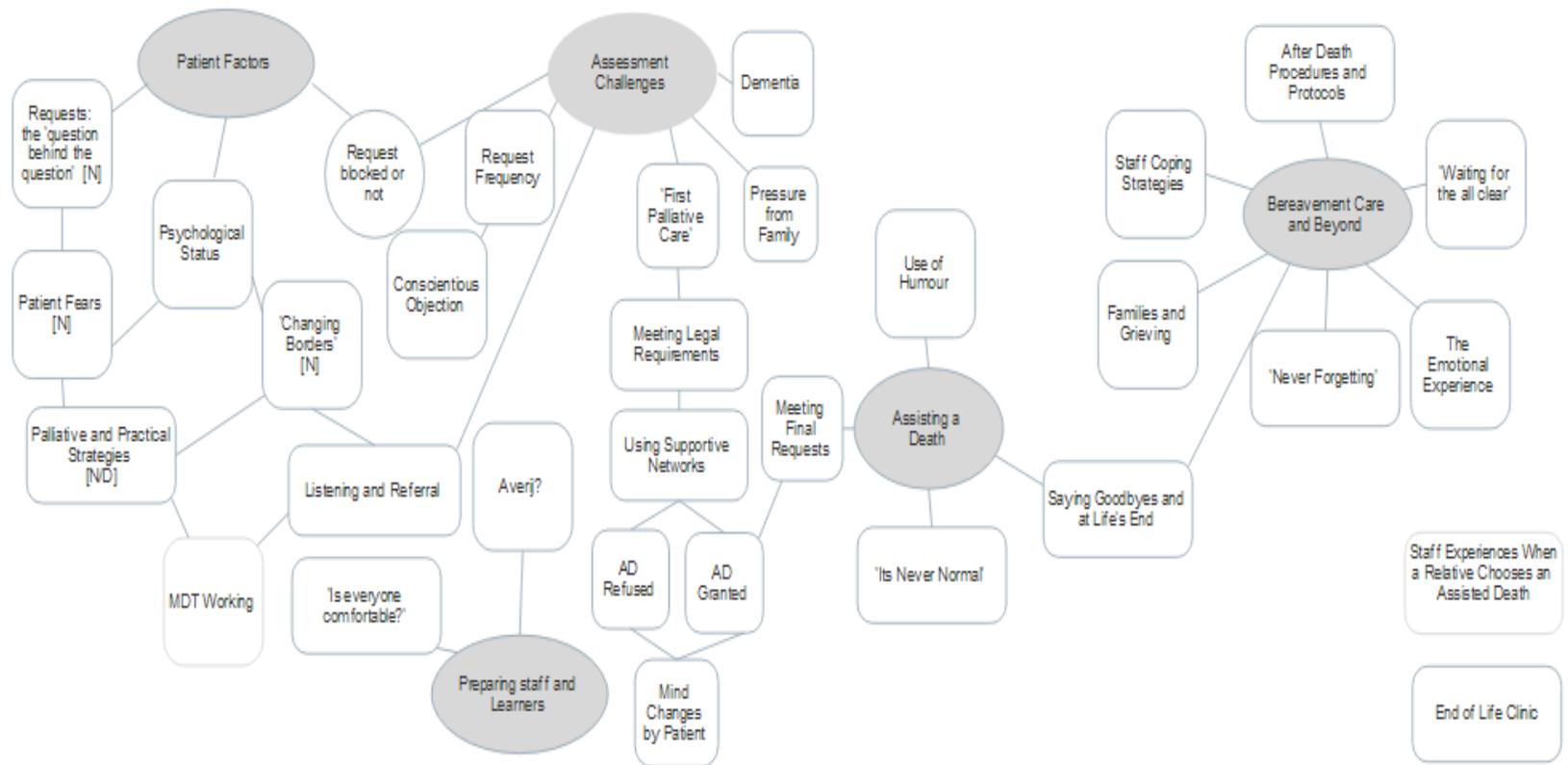


## Appendix 11: Phase 2: Braun and Clarke (2006)

### Initial Codes

Initial Codes	
<p>           'Typical Patients'            Patient Characteristics            Frequency of Requests            Patient Requests            Clinical Condition            Psychological Status            'It's not for everyone'            'Changing Borders': Deciding a Date            'Talking it through with Patients'            Organisational Policy Issues            Assessment Challenges            Assessing Patient Seriousness            Granting Requests            Refusing Requests            Length of Assessment Period            Ethical Issues            Negotiating other Solutions            Assessing and Dealing with Families            Clinical Environments            Multidisciplinary Assessment            Supportive networks            Preparing Staff            Managing the Experience            Legislation and Legality Issues         </p>	<p>           Preparing Learners            'Is everyone comfortable?'            'The doctors have to do it.'            Preparing, Coping with and Supporting Families            Patient care and Meeting Final Requests            Use of Humour            'It's never normal'            The Emotional Experience for Staff            Feeling Close and Learning from Patients            Multi-disciplinary Support and Team Working            At the End - Saying Goodbyes            Coping Afterwards and Dealing with Emotions            After Death Procedures and Protocols            Families and Grieving            Supporting other Patients after the Death            Staff Coping Strategies            Beyond Death            'Never forgetting'            Assisted Dying and Religion            The Dilemma of Dementia            Patient Pressures            End of Life Clinic         </p>

## Appendix 12: Thematic Map: Searching for Themes



## Appendix 13: Phase Five: Defining Main Themes

Theme	Subthemes
<p><b>Assessment and Its Challenges:</b>            Assessment, a multifaceted and challenging process, starts when staff hear an expression of interest in an assisted death. This activates a wide range of activities which result in either resolving the request by other means, refusing it or the request being granted.</p>	Workload Issues: Frequency of Requests Exploration and Negotiation Perceptions of Patients' Characteristics Demanding Patients and Families 'First palliative care' Conscientious Objection Meeting Legal Requirements Refused Requests 'Changing borders and minds' Psychological Status Assessing and Supporting Families The End of Life Clinic
<p><b>Preparing Staff and Learners</b>            After assessment, if a request is granted, the focus shifts back to the staff who use supportive networks to prepare themselves for the death.</p>	Staff Preparation: 'Averij' Use of Supportive Networks 'Is everyone comfortable?'
<p><b>Assisting a Death</b>            Careful management characterises assisted deaths with activities to support the patient and their family, and staff.</p>	Meeting Final Requests Managing the Death Saying Goodbyes and Life's End Lethal Medication 'It's never normal' The Use of Humour
<p><b>Bereavement Care and Beyond</b>            Post death care focuses on legal procedures and bereavement support for the family, but the death has a psychological impact on staff who need a recovery period time to resolve their feelings.</p>	After-death Procedures Legal or Not?: 'Waiting for the all clear' Emotional Experience for Staff and Coping Strategies Bereavement Care : 'Doing a bit extra' Families and Grieving 'Never forgetting'

## Appendix 14: Research Summary: Participant Information Sheets



Assisted Dying in the Netherlands: The experience of healthcare professionals in a hospice and chronic disease care centre.

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

### **What is the study about?**

The purpose of this study is to improve our knowledge of the experiences of healthcare professionals of euthanasia in the Netherlands. The study has gathered information from individual interviews to gain insight into the experience of healthcare professionals who participate or abstain from euthanasia in practice. This information will help me, and the wider society, to learn from your experiences.

### **Why have I been approached?**

You have been invited to an Open Invitation Research Summary because you work at the Name Withheld and have experience of caring for patients who have chosen or discussed euthanasia. You will review my provisional findings and have the opportunity to discuss and add more information if you wish. We would like to hear the views of staff working in a healthcare setting as it will help us to gain valuable insights into this complex area of care.

### **Do I have to take part?**

No. It's completely up to you to decide whether or not you take part. Your participation is voluntary and you can withdraw from the project during the research process if you wish without giving any reasons.

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

If you decide you would like to take part, you will have the opportunity to review and discuss my research findings with other medical, nursing and therapy staff. This will take approximately 60 to 90 minutes in total. You can withdraw if you wish at any time although it may not be possible to withdraw all of your verbal interactions made whilst the summary was in process.

### **Will my personal details be confidential?**

Every effort will be made to ensure your personal information remains confidential. Data management will be the responsibility of me and will be the property of Lancaster University. With your permission data will be audio recorded during the summary and will be stored securely.

Audio recordings will be deleted from the recording device after being downloaded on a computer. The files on the computer will be encrypted (that is no-one other than me,

the researcher, will be able to access them) and the computer itself will be password protected

- All personal data relating to you will be stored separately from transcripts on a mobile storage device that is encrypted and password protected.
- Your transcribed data will be made anonymous by removing any identifying information including your name. All hard copies of transcripts and any additional notes will be kept in a locked cabinet when not in use.
- If there is any possibility of you being identified by any comments you have made perhaps, for example if you are a conscientious objector to euthanasia, this will be discussed with you prior to using your comments.
- All data held on computer will be destroyed after five years from the end of the study using software to ensure it cannot be retrieved from hard drives. Mobile storage devices will be physically destroyed. If data is deemed to be of historical interest it may be archived in the United Kingdom if a suitable repository is available at the time. Confidentiality regulations will still be applied.

There are some limits to confidentiality; if what is said in the summary makes me think that you, or someone else, are at significant risk of harm, I will have to break confidentiality and speak to, in the first instance, my supervisors about this and take appropriate action if necessary.

#### **What will happen to the results?**

The results will be summarised and reported in a PhD thesis some of which will be submitted for publication in an academic or professional journal if they are likely to be helpful or of interest to other healthcare professionals.

#### **Are there any risks?**

There should be no risks anticipated with participating in this study. It is, however, a sensitive topic area and if you wish to discuss your involvement further please contact me. If you become distressed during the summary the recording will stop and you will be able to leave if you wish to do so. If you experience any further distress following participation you are encouraged to inform me and to access the resources provided at the end of this sheet.

#### **Are there any benefits to taking part?**

Although you may find participating interesting, there are no direct benefits in taking part although you may find it helpful to have the opportunity to discuss your experiences.

#### **Who has reviewed the project?**

This study has been reviewed by the Lancaster University's Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee. It has also been seen by the Maastricht University's Medical Ethics Committee (METC 12-5-043). Your organisation has agreed to participate in the research.

#### **Where can I obtain further information about the study if I need it?**

If you have any questions about the study, please contact the researcher:  
Mrs Debbie Lewis, Researcher/PhD Student, Lancaster University

the researcher, will be able to access them) and the computer itself will be password protected

- All personal data relating to you will be stored separately from transcripts on a mobile storage device that is encrypted and password protected.
- Your transcribed data will be made anonymous by removing any identifying information including your name. All hard copies of transcripts and any additional notes will be kept in a locked cabinet when not in use.
- If there is any possibility of you being identified by any comments you have made perhaps, for example if you are a conscientious objector to euthanasia, this will be discussed with you prior to using your comments.
- All data held on computer will be destroyed after five years from the end of the study using software to ensure it cannot be retrieved from hard drives. Mobile storage devices will be physically destroyed. If data is deemed to be of historical interest it may be archived in the United Kingdom if a suitable repository is available at the time. Confidentiality regulations will still be applied.

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#### **Where can I obtain further information about the study if I need it?**

If you have any questions about the study, please contact the researcher:  
Mrs Debbie Lewis, Researcher/PhD Student, Lancaster University

Work Address: Birmingham City University, Bevan 224, Westbourne Road, Edgbaston,  
Birmingham. B15 3TN. Email: [deborah.lewis@bcu.ac.uk](mailto:deborah.lewis@bcu.ac.uk). Or tel: 44 121 331 7160.  
Skype: debbielewisbcu

### **Complaints**

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to me you can contact:

Professor Bruce Hollingsworth  
Head of Division of Health Research  
Email: [b.Hollingsworth@lancaster.ac.uk](mailto:b.Hollingsworth@lancaster.ac.uk)  
Tel: (01524) 594154  
C63 Furness College  
Lancaster University  
Lancaster  
LA1 4YG

Professor Roger Pickup [Chair]  
Associate Dean for Research  
Email: [r.pickup@lancaster.ac.uk](mailto:r.pickup@lancaster.ac.uk)  
Tel: (01524) 593746  
B79 Furness College  
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, you will be able to talk to the Confidential Advisor provided for all employees in The Netherlands, and accessible via your organisation, to obtain counselling and psychological support if necessary.

**Participant Information Sheet for Amendment**  
**[Previous Participants]**



Assisted Dying in the Netherlands: The experience of healthcare professionals in a hospice and chronic disease care centre.

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

**What is the study about?**

The purpose of this study is to improve our knowledge of the experiences of healthcare professionals of euthanasia in the Netherlands. The study has gathered information from individual interviews to gain insight into the experience of healthcare professionals who participate or abstain from euthanasia in practice. This information will help me, and the wider society, to learn from your experiences.

**Why have I been approached?**

You have been invited because you previously participated in the research being interviewed by me in 2013. These interviews have been transcribed and analysed to produce provisional findings describing the experiences of healthcare professionals. You are invited to an Open Invitation Research Summary to listen to my provisional findings. Alternatively, after completing a Consent Form, you may receive the PowerPoint presentation to add additional comments by secure email if you wish.

**Do I have to take part?**

No. It's completely up to you to decide whether or not you take part. Your participation is voluntary and you can withdraw from the project during the research process if you wish without giving any reasons.

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

If you decide you would like to take part, you will have the opportunity to review and discuss my research findings with other medical, nursing or therapy staff. This will take approximately 60 to 90 minutes in total. You can withdraw if you wish at any time although it may not be possible to withdraw all of your verbal interactions made whilst the summary was in process.

**Will my personal details be confidential?**

Direct quotes from your interview will not be included in the Summary Presentation and you will not be identified as a previous participant in the research. Every effort will be made to ensure your personal information remains confidential. Data management will be my responsibility and will be the property of Lancaster University. With your permission data will be audio recorded during the summary and will be stored securely.

- Audio recordings will be deleted from the recording device after being downloaded on a computer. The files on the computer will be encrypted (that is no-one other than me, the researcher, will be able to access them) and the computer itself will be password protected.
- All personal data relating to you will be stored separately from transcripts on a mobile storage device that is encrypted and password protected. Email communication will be encrypted.
- Your transcribed data will be made anonymous by removing any identifying information including your name. All hard copies of transcripts and any additional notes will be kept in a locked cabinet when not in use.
- If there is any possibility of you being identified by any comments you have made perhaps, for example if you are a conscientious objector to euthanasia, this will be discussed with you prior to using your comments.
- All data held on computer will be destroyed after five years from the end of the study using software to ensure it cannot be retrieved from hard drives. Mobile storage devices will be physically destroyed. If data is deemed to be of historical interest it may be archived in the United Kingdom if a suitable repository is available at the time. Confidentiality regulations will still be applied.

There are some limits to confidentiality; if what is said in the summary makes me think that you, or someone else, are at significant risk of harm, I will have to break confidentiality and speak to, in the first instance, my supervisors about this and take appropriate action if necessary.

#### **What will happen to the results?**

The results will be summarised and reported in a PhD thesis some of which will be submitted for publication in an academic or professional journal if they are likely to be helpful or of interest to other healthcare professionals.

#### **Are there any risks?**

There should be no risks anticipated with participating in this study. It is, however, a sensitive topic area and if you wish to discuss your involvement further please contact me. If you become distressed during the summary the recording will stop and you will be able to leave if you wish to do so. If you experience any further distress following participation you are encouraged to inform me and to access the resources provided at the end of this sheet.

#### **Are there any benefits to taking part?**

Although you may find participating interesting, there are no direct benefits in taking part although you may find it helpful to have the opportunity to discuss your experiences.

#### **Who has reviewed the project?**

This study has been reviewed by the Lancaster University's Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee. It has also been seen by the Maastricht University's Medical Ethics Committee (METC 12-5-043). Your organisation has agreed to participate in the research.

#### **Where can I obtain further information about the study if I need it?**

If you have any questions about the study, please contact the researcher:

Mrs Debbie Lewis, Researcher/PhD Student, Lancaster University  
Work Address: Birmingham City University, Bevan 224, Westbourne Road, Edgbaston,  
Birmingham. B15 3TN.  
Email: [deborah.lewis@bcu.ac.uk](mailto:deborah.lewis@bcu.ac.uk). Or Tel: 44 121 331 7160.  
Skype: debbielewisbcu

### **Complaints**

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to me you can contact:

Professor Bruce Hollingsworth  
Head of Division of Health Research  
Email: [b.hollingsworth@lancaster.ac.uk](mailto:b.hollingsworth@lancaster.ac.uk)  
Tel: (01524) 594154  
C63 Furness College  
Lancaster University  
Lancaster  
LA1 4YG

Professor Roger Pickup [Chair]  
Associate Dean for Research  
Email: [r.pickup@lancaster.ac.uk](mailto:r.pickup@lancaster.ac.uk)  
Tel: (01524) 593746  
B79 Furness College  
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, you will be able to talk to the Confidential Advisor provided for all employees in The Netherlands, and accessible via your organisation, to obtain counselling and psychological support if necessary.

## Appendix 16: Transcript Open Invitation Research Summary

Segment of Transcript Recorded on April 22<sup>nd</sup> 14.45 to 15.30 hrs

**DL:** I explained reasons for the topic, ethical approval granted, need for the verification of my provisional results, not generalizable, but may be helpful to others. I explained the process of my research and that I can add to my provisional results and it is Ok for staff to disagree with me.

*Staff: Query as to whether or not it is legal in Switzerland. Earlier a doctor in a corridor had stated his view the need for travel to Switzerland was unethical for UK patients in his view and needed to be resolved by having permissive legislation. This was pointed out by a member of the attending staff.*

**DL:** I gave an explanation of my understanding of assisted dying in Switzerland.

*Staff: Patients assisted by whom? And after an explanation added: "With a medical background I hope?"*

**DL:** I explained this may not be the case although a patient will be assessed by a doctor, but assisted to take the medication themselves by a volunteer from a self-help organisations.

*Staff: "A terrible way to die" was one participant's response to having a 'time slot' and having to travel aboard.*

**DL:** I explained the current status of draft legislation in the House of Lords.

*Staff: Discussion in Dutch about the meaning of a Family Court.*

**DL:** Reviewed my thematic analysis measures and the initial, intermediate and final conceptual categories I arrived at. The need to be unbiased as to whether or not assisted should be allowed in the UK. The participants were encouraged to put up a hand or to stop me if they wish to disagree or ask a question. I explained the removal of staff experiences with relatives who requested an assisted death and then I gave a broad overview of the final categories starting with Patient Factors and moving on to the others.

*Staff: One nurse in agreement that assisted dying requests from older patients and nods from others when issue of patients with chronic disease altering their own borders came up. Some laughter amongst group as one participant is nodding off.*

## Appendix 16: Ethical Approvals and Permission to Proceed

LANCASTER  
UNIVERSITY



Applicant: Deborah Lewis  
Supervisors: Drs Anne Grinyer, Nancy Preston  
Department: DHR

30 January 2013

Dear Deborah, Anne and Nancy,

**Re: Euthanasia in Holland: the experience of healthcare professionals in a hospice and chronic disease care centre**

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 [ethics@lancaster.ac.uk](mailto:ethics@lancaster.ac.uk)) if you have any queries or require further information.

Yours sincerely,

Sarah Taylor  
Secretary, University Research Ethics Committee

Cc Professor T McMillan (Chair, UREC); Professor Paul Bates (Chair, FHMREC)

Research Support Office  
Research and Enterprise Services

Lancaster University  
Bowland Main  
Lancaster LA1 4YT  
United Kingdom

Tel: +44 (0) 1524 592002  
Fax: +44 (0) 1524 593229  
Web: <http://www.lancs.ac.uk>

**Email received on Frid 10/08/2012 09:23**

**Van:** Knip - Hilton A.M. (Anne) [anne.hilton@mumc.nl] namens  
MECsecretariaat [secretariaat.mec@mumc.nl]

**Verzonden:** vrijdag 10 augustus 2012 9:33

**To:** Deborah Lewis

**Cc:** Janssen, Daisy

**Onderwerp:** RE:METC 12-5-043

Ref.: What are the experiences, attitudes of and the impact on  
healthcare professionals caring for patients who chose euthanasia  
or physician-assisted dying in a Hospice and an Advanced Care  
Centre for chronic disease organ failure in the Netherlands (METC  
12-5-043)

Dear ms. Lewis,

Your above-mentioned research proposal was discussed in the  
meeting of the executive committee of the METC azM/UM on 8th  
August 2012. The committee concluded that your research  
proposal does not, under Dutch law (WMO), require medical  
ethical approval, because your research involves interviews with  
health care workers. There is no participation of patients in your  
research.

Your research involves assessment of routine care. The METC  
azM/UM does not need to take any further action regarding your  
research proposal.

You are kindly requested to change the wording in the protocol and  
the information for the participants with regard to the necessity  
to gain approval from the medical ethics committee.

We hope that this answers your question and we wish you success  
with your research in the Netherlands.

Yours sincerely, on behalf of the METC azM/UM,

Anne M. Hilton (mw)

secretaris METC azM/UM

Postbus 5800

6202 AZ Maastricht

Applicant: Deborah Lewis  
Supervisor: Dr Anne Grinyer, Dr Nancy Preston  
Department: DHR

20 March 2015

Dear Deborah, Anne and Nancy,

**Re: Assisted dying in the Netherlands: The experience of healthcare professionals in a hospice and chronic disease care centre (new title).**

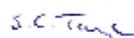
Thank you for submitting your amendment for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The amendment was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 [ethics@lancaster.ac.uk](mailto:ethics@lancaster.ac.uk)) if you have any queries or require further information.

Yours sincerely,



Sarah Taylor  
Secretary, University Research Ethics Committee

Cc: Fiona Aiken, University Secretary, Professor Roger Pickup (Chair, FHMREC); Prof Stephen Decent (Chair, UREC).

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## Appendix 17: Consent Form

### Consent Form for Individual Interviews/Open Invitation Research Summary [Delete Option] Euthanasia in the Netherlands: The experience of staff in a Hospice and Chronic Disease Care Centre

We are asking if you would like to take part in a research project to increase our understanding of the experiences of participating in the care of patients who chose euthanasia. Before consenting to participate please 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, Mrs Debbie Lewis.

I confirm that I have read the information sheet and fully understand what is expected of me within this study. Please initial the box after each statement.

1.	I confirm that I have had the opportunity to ask any questions and to have them answered.	
2.	I understand that my interview/Open Invitation Research Summary will be audio recorded and then made into an anonymised written transcript	
3.	I understand that audio-recordings will be kept until the research project has been examined.	
4.	I understand that I am not obliged to take part in this study and can withdraw my participation before, during, or up to 2 weeks after my interview/Open Invitation Research Summary	
5.	I understand that the information from my interview/Open Invitation Research Summary will be pooled with other participants' responses, anonymised and may be published	
6.	I consent to information and quotations from my interview /Open Invitation Research Summary being used in reports, conferences and training events and understand if personal identification may be possible this will be discussed with me.	
7.	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 may need to share this information with her research supervisor and take appropriate action if necessary.	
8.	I consent to Lancaster University keeping written transcriptions of the interview/Research Summary for 5 years after the study has finished.	
9.	I consent to take part in the above study.	

Name of Participant \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

Name of Researcher \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_