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Exploring experiences of seeking or providing the medical documentation required for an assisted dying application

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Sneaking off to Switzerland:

Exploring experiences of seeking or providing the medical documentation required for an assisted
dying application

Dr Paul Teed

A dissertation submitted to the University of Bristol in accordance with the requirements for
award of the degree of
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Abstract

Within the United Kingdom, assisted dying is a hotly contested (and often divisive) topic of contemporary political debate. Despite the level of attention assisted dying receives and considering the consequences for all involved, very little is known about the experiences of those seeking assisted deaths abroad in Switzerland within the regulatory status quo.

As part of Switzerland's assisted dying application process, prospective applicants must provide medical documentation to comply with Swiss criminal law. General practitioners have reported legal fears and uncertainty about providing this documentation, while applicants report inconsistent reactions from healthcare professionals after disclosing their reasons for seeking documentation.

My thesis explores 24 people's experiences of seeking or providing the required medical documentation for an assisted dying application. To help mitigate regulatory fears (for potential participants and myself as the researcher), I developed a novel recruitment protocol that offered anonymity during recruitment.

My conceptual framework draws on the growing body of literature that describes assisted dying as a discursive process, paying attention to the asymmetric relations in power between healthcare professionals and patients. I present a critical reflexive thematic analysis that captures the furtive nature of seeking an assisted death abroad and the attempt to retain control over a pervasive sense of risk accompanying the disclosure of the reasons for seeking medical documentation.

Sneaking off to Switzerland describes strategic disclosure of the reasons for seeking documentation and a self-silencing that may contribute to the reinforcement of the social stigma surrounding suicide and risk the marginalization of those holding a wish to hasten death (WTHD) yet further.

Acknowledgments

I am primarily indebted to those who participated in my study, to whom this is my only opportunity for further direct contact. If you read my thesis and maybe even recognize yourselves within it, I hope I have faithfully brought across the thrust of your collective experiences. As a practicing member of the medical profession, I feel it is so important that I state (publicly and from the outset) how sorry I am that many of you have experienced some of the things you have shared with me. Healthcare professionals must do better at a time when they are most needed.

This thesis would simply not exist without my supervisors' (Prof. G. Feder, Prof. J. Ives, Dr A. Malpass, and Prof. H. Carel) support, guidance, and advice over the many, many years. I have had the best team, and meeting up for supervision has been fun while leaving me in awe of your skills (academic, not tennis). For those still at the University of Bristol, the university should be so thankful that they have you. For those who are not, I rage at the precarity of academia and what seems to be an unjust epistemic hierarchy within research methodologies.

Finally, to my other half (the Ayatollah, Milly's BFF, Barney McGrew, Kitty B, Deanie, Jean-Bernard's second favourite person but Trev's favourite, also known to others as Toad or the K-bot), I would simply not exist without you. Bring on holiday.

Author's declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's Regulations and Code of Practice for Research Degree Programmes and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

SIGNED: DATE: 01/01/2024

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Publications

The publications that have arisen from my research are listed below. Within my thesis, I signpost one place where I quote a brief passage from one of these articles.

Articles

Teed, P (2017). Access to medical records for an assisted death: clarifying guidance. *British Journal of General Practice* 2017; 67 (664): 515. DOI: <https://doi.org/10.3399/bjgp17X693305>

Opinion pieces

Teed, P (2017). Why doctors need to improve the way we discuss assisted dying. *The Conversation*. Published 23/11/2017. Found online at: <https://theconversation.com/why-doctors-need-to-improve-the-way-we-discuss-assisted-dying-87875>

Written submissions

January 2023. The Health and Social Care Committee inquiry into assisted dying. Found at: <https://committees.parliament.uk/writtenevidence/117076/html/>

List of abbreviations

AD	Assisted dying
AS	Assisted suicide
BMA	British Medical Association
CPS	Crown Prosecution Service
GMC	General Medical Council
GP(s)	General practitioner(s)
HCP(s)	Healthcare professional(s)
ICO	Information Commissioner's Office
SAHD	Schedule of attitudes towards hastened death
SAMS	Swiss Academy of Medical Sciences
SAR	Subject Access Request
UK	United Kingdom
US	United States (of America)
VE	Voluntary euthanasia
WTHD	Wish to hasten death

1 Introduction

1.1 Introductory remarks

When I began my research in 2016, only a small number of jurisdictions worldwide permitted assisted dying (AD) in one form or another: Switzerland, The Netherlands, Belgium, Luxembourg, Columbia, Canada, and several states in the United States of America (USA). Seven years later (after my studies were interrupted by the COVID-19 pandemic), this list has grown further to include Austria, Germany, Portugal, Spain, New Zealand, further states within the USA, and all Australian federal states.

Within all nations of the United Kingdom (UK), AD is illegal and remains so despite multiple attempts at changing the law over the last 90 years (the first attempt at permissive legislative change in Parliament was in 1936) (Black, 2016). Notably, proposals for permissive change were last rejected in both Westminster (legislating for England and Wales) and Scottish Parliaments in 2015. However, with further votes on permissive change widely expected to take place in the Scottish Parliament and the Crown Dependencies of Jersey and the Isle of Man in 2024, AD seems set to remain in the limelight.

It is my contention that regardless of debates on whether permissive legislation *ought* to be introduced, further knowledge is urgently needed about what *is* already happening within the regulatory status quo. UK-focused literature has previously tended to come from a predominantly legal or ethical background, with scant research on how people experience the regulatory status quo. Subsequently, I focus on one phenomenon often seen in the national media and which has developed within the regulatory status quo: the small number of UK citizens seeking assisted deaths in Switzerland. Since the first recorded assisted death of a UK citizen in Switzerland in 2002, 531 UK citizens have received an assisted death via one association alone, Dignitas (Dignitas, 2023a)¹.

As part of the AD application process, applicants must provide medical documentation to comply with Swiss criminal law. General practitioners (GPs) have reported fears and uncertainties about providing this documentation (Pulse, 2012), with subtle regulatory tensions needing to be balanced in practice. Meanwhile, applicants have reported inconsistent reactions from healthcare professionals (HCPs) after disclosing their desire to seek the option of an assisted death abroad, including the denial of access to their medical records (Riley and Heir, 2017). This seeking or providing the medical documentation required for an AD application is the focus for my thesis.

¹ Latest figures show there are currently 1528 UK-based members of Dignitas (Dignitas, 2023b), and 175 of Lifeircle (Watson, 2023).

I have three key aims for my thesis:

1. To illuminate an otherwise overlooked issue within the regulatory status quo by drawing on a growing body of literature that describes AD as a discursive process (Magnusson, 2002; Starks et al., 2007; Ohnsorge, Gudat and Rehmann-Sutter, 2014; Brooks, 2019; Norwood, 2020; Young et al., 2021). Whilst I shine a light on specific experiences within this highly debated bioethical issue (AD), I will not undertake a normative-ethical analysis about them. As such, my thesis is largely descriptive and I will steer clear of normative claims surrounding the desirability (or not) of permissive legislation.
2. To provide recommendations that may help contribute to de-escalating the reported fears/uncertainties of HCPs, even out inconsistencies in care, and ensure that applicants gain access to the documentation they are entitled to receive.
3. AD is a topic that spans multiple academic disciplines (e.g., legal, ethical, philosophical, clinical, sociological) and interests many people from all walks of life. As such, my last aim is for my thesis to reflect this by being multi-disciplinary and readable by a lay audience.

1.2 Locating the researcher: impetus

I became exasperated at stories from colleagues regarding the teaching on AD within post-graduate training. One trainee general practitioner (GP) I know reported receiving only one article from one organization's political campaign material during their palliative medicine placement as representing 'the facts'. In a regional teaching session, another trainee reported the group being given a scenario of a request for copies of medical records from a patient who wanted to use them in a Swiss AD application. At the end of the session, a vote was taken to gauge who thought copies should or should not be provided, rather than exploring the regulatory guidance on the issue.

I also began to perceive some senior medical professionals using their platforms, not as educationalists, but as reductive and biased activists. I perceived a democratic gap in how the British Medical Association (BMA) formed its (opposed) position on AD (between its membership and their representatives)². I subsequently became a member of Healthcare Professionals for Assisted Dying (a sub-section of the permissive legislative change lobby group Dignity in Dying) as they campaigned for

² The BMA voted to change this position in 2021 (to one of neutrality) following a non-binding indicative survey of its membership (BMA, 2021).

professional bodies to have neutral organizational positions. I became vocal on social media, almost becoming the very thing that led to my involvement in the first place. In an attempt to balance what I perceived to be selective views I began behaving in the very same way, albeit from the other side of the debate.

Through my interactions on social media, I became subject to a wide variety of (extreme) comments. I experienced what doctors have previously reported in one study from The Netherlands, being treated as a hero by patients/family members of those applying for AD, yet as a criminal (or a Nazi eugenicist) by anti-AD campaigners (Norwood, 2020). I met many people who had either experienced the assisted death of a loved one or actively sought the option for themselves. I wondered why these people were speaking to *me* about their illnesses, symptoms, and fears, and not their own doctors or specialists.

I carried out a scoping review of the literature that utilized a broad search strategy (Appendix One) to be sensitive to as many relevant studies as possible (at the expense of a lack of specificity). However, I found very little on experiences from the UK within the regulatory tatus quo, identifying a gap in the knowledge base. My research journey had begun.

1.3 Thesis structure

In **chapter two**, I follow on from this brief introduction to clarify the regulatory setting for my thesis. I begin by addressing my terminological choices and specifying what Swiss AD involves. I discuss the Swiss regulatory background that creates the need for applicants to provide medical documentation and subsequent subtle tensions within the regulatory status quo in the UK. Specifically, I highlight how HCPs must balance professional regulatory tensions surrounding assistance with an individual's data rights (when providing medical documentation).

Chapter three continues to frame my thesis by reviewing the phenomenon at the heart of my thesis: seeking and requesting the option of assisted death. I first introduce the literature on the wish to hasten death (WTHD), revealing complex and sometimes contradictory motivations and intentions behind a WTHD. I discuss how a WTHD does not necessarily end in an assisted death nor does it necessarily mean an intention to die. Instead of a one-off final event, a growing body of literature describes AD as a discursive process involving practices of inclusion and exclusion that can reinforce social power relations. Lastly, I relate these understandings to the comparatively scant UK-based research and present the research question that guides my study.

In **chapter four** I discuss the methodology I utilize to answer my research question. I address the theoretical background to developing a critical reflexive thematic analysis by unpacking what I mean by the term *critical* and reflect on my own background. I identify a concern regarding my professional role and the potential for reports of practices that contravene professional guidance or criminal law during data collection. I discuss the importance of anonymity within qualitative research and subsequently present a novel study protocol which offered anonymity at/from recruitment for potential participants.

Chapter five provides the main empirical findings from my study. I present a critical thematic analysis of 24 people's experiences of seeking, or providing, medical documentation for use in an application for an assisted death in Switzerland. I develop two key themes, *the dangerous ground* and *sneaking off to Switzerland*. *The dangerous ground* captures a pervasive sense of risk and precariousness accompanying the disclosure of a WTHD whilst seeking medical documentation. *Sneaking off to Switzerland* then captures the furtive nature of seeking an assisted death in Switzerland and the transformative descriptions of receiving a provisional green light from a Swiss AD association.

In **chapter six** I discuss the relevance of my findings alongside reflections on the limitations and impacts of my thesis. I situate the findings of my study within the literature on AD as a discursive process and introduce a theoretical lens to help make sense and explain my findings further. This lens highlights *sneaking off to Switzerland* as a form of self-silencing emanating from the experiences of *the dangerous ground*. I identify a concerning implication: the reinforcing of the social stigma surrounding suicide.

2 Clarifying assistance

2.1 Introduction

In this chapter, I provide the relevant regulatory background for the setting of my thesis, seeking or providing the medical documentation required within an application for an assisted death. I begin by discussing the terminological choices I have made surrounding the usage of the term assisted dying (AD). I then outline what Swiss AD involves before discussing the Swiss regulatory origins of the requirement for medical documentation within the application process. I then move on to the complexities of the UK regulatory background to discuss the different regulatory jurisdictions that impact on the provision of medical documentation. This leads to the importance of the Crown Service Prosecution (CPS) guidelines on assistance and their role in creating a subtle tension with data rights that HCPs must balance in practice.

2.2 Disputed definitions

The language used to designate permissive AD regulatory frameworks around the world varies: aid in dying (USA), death with dignity (USA), voluntary assisted dying (Australia), medical assistance in dying (Canada), end-of-life choice (New Zealand), euthanasia (Belgium and The Netherlands) and assisted suicide (Belgium, The Netherlands and Switzerland). Swiss AD associations themselves use different English terminologies from each other: accompanied suicide (Dignitas), assisted voluntary death (Lifecircle), self-determined death (EX International), and voluntary assisted dying (Pegasos).

While this terminological variety originates from unique cultural, legal, and political contexts (Lewis, 2007) it is difficult to distinguish from terminology alone what practices they describe (Otlowski, 1997; Ost, 2003; Keown, 2005; Huxtable, 2007; Lewis, 2007; McLean, 2007; Huxtable, 2013). Blurring the matter further, the way these terms are perceived by a hearer or utilized by a speaker can reflect the deeply held cultural and moral beliefs of individuals rather than the specifics of the frameworks themselves (Thulesius et al, 2013; Richards, 2016; Koksvik et al., 2020; Young et al., 2021). In short, different terms can mean different things, and even the same term can mean different things to different people.

Regarding this lack of precision and clarity, Keown (2005) argues that AD is a euphemistic term that "obfuscates important legal, practical, and ethical distinctions". Keown's specific charge is that AD conflates two terms of importance: assisted suicide and voluntary euthanasia:

Assisted suicide (AS): A person (d) aids another individual (p) to deliberately cause their own death (at p's request and for the sake of p's prudential good). For example, d inserts a venous catheter into one of p's veins and connects this to an intravenous solution that contains a life-ending quantity of barbiturates. Subsequently, p flips a switch so that the barbiturate solution flows into p's own body, and p subsequently dies.

Voluntary euthanasia (VE): A person (d) deliberately causes another individual's (p) death (at p's request and for the sake of p's prudential good). For example, d inserts a venous catheter into one of p's veins and connects this to an intravenous solution that contains a life-ending quantity of barbiturates. Subsequently, d flips a switch so that the barbiturate solution flows into p's body, and p subsequently dies (adapted from Black, 2016).

By providing these definitions, I seek to make it clear that the final act of assistance involves the intentional ending of a person's life, regardless of whether this act is performed by the applicant (AS) or by another (VE). Traditionally, these definitions serve as a catalyst to discuss the many legal, ethical and practical distinctions Keown is referring to, including (but not limited to): who performs the final act, the intentions motivating an act, acts of commission vs omission, the voluntariness of a request, mental capacity, what or who defines a person's prudential good and the characteristics of both the assistor (e.g., whether a doctor is involved) and the receiver of assistance (e.g., eligibility criteria).

For a shared understanding going forward, I utilize the term AD throughout my thesis as an umbrella term incorporating both AS and VE. I utilize AD as an umbrella term specifically due to the lack of precision that Keown has criticized it for. While important, I contend that these terminological distinctions provide only a limited conceptual understanding of AD as they tend to orientate focus on the final causal act of death. A terminological focus on the final act exemplifies the fact that the backgrounds of the bulk of the UK literature on AD come are largely legal or ethical. Instead, AD typically involves an application process consisting of multiple interactions over a prolonged period.³ This continual requirement to re-engage with others, common to all permissive frameworks, is central to an increasing body of literature that describes AD as a discursive process (Magnusson, 2002; Starks et al., 2007; Ohnsorge, Gudat and Rehmann-Sutter, 2014; Brooks, 2019; Norwood, 2020; Young et al.,

³ Several jurisdictions allow for a shorter assessment period before the final act of death; however, death is usually expected to occur within a shorter, more imminent timeframe.

2021). It is this understanding of AD as a discursive process which frames my thesis and not the details surrounding the final causal act of death (to which I will return in the next chapter).

Using a broad concept allows me to examine international experiences of processes across multiple jurisdictions despite heterogeneous regulatory frameworks. An umbrella usage is also inclusive, reflecting the language used by those seeking the option of an assisted death.⁴ However, it is important to point out that this usage is at odds with how AD was conceptualized in the *Assisted Dying (No.2) Bill*, voted down in the Parliament of Westminster in 2015 and the proposed *Assisted Dying for Terminally Ill Adults (Scotland) Bill* widely expected to be voted on in 2024 in the Scottish Parliament. Instead, these Bills define AD as meaning AS/self-administration (only), which restrict eligibility to only those individuals with a (time-limited) terminal prognosis. The lack of accuracy in an umbrella usage of the term AD also matters when it comes to the specifics of what Swiss AD practice does and does not involve. As such, before going any further I shall detail what Swiss AD practices involve due to it being the destination jurisdiction for UK citizens seeking the option of an assisted death.

2.3 Swiss assistance

The process of UK citizens seeking the option of an assisted death in Switzerland begins via paid membership of one of the three associations that provide an assisted death for foreign residents. Swiss AD associations were first formed in the late 1980s and began offering AD to Swiss citizens in the early 1990s (Fischer et al., 2008). In 1998, Dignitas became the first association to offer AD for foreign residents, with two other associations currently offering the possibility of AD for foreign citizens: Pegasos and EX International. A fourth association, Lifecircle, used to offer another option, but they ceased taking on new members as of November 2022 (Watson, 2023). While Dignitas is the largest and most well-known (so much so it is almost synonymous with Swiss AD practices), it is the newest association, Pegasos (formed in 2019), that will likely impact future practice as it claims to

⁴ I purposefully avoid the use of the word 'tourism' to describe people travelling across international borders from the UK to seek AD in Switzerland. This term has been used previously despite the fact it decreases the credibility of a person's choice (e.g., by invoking privileged recreational activities). It is also an inaccurate term, as a tour connotes a return trip which those who seek an assisted death in Switzerland do not make (Huxtable, 2009; Haesen, 2018; Sperling, 2019).

conduct its application process in English (as its first language) and make the application process easier by accepting electronic submissions (Pegasos, 2023a).

After joining a Swiss AD association, the next step towards assistance involves an application for the consideration of AD, typically involving another more significant cost (£000s). Submitting requirements can vary slightly between associations but typically consist of a personal account from the applicant (attesting to their reasons for requesting AD) and a long list of administrative documents. These documents typically include proof of residence, birth certificates, marriage certificates, and (relevant to my thesis) medical documentation (Dignitas 2023c; Pegasos, 2023b).

It can then take weeks to months for a Swiss AD association to process an application from the UK. Multiple discussions with the association staff take place, on top of two discussions with Swiss doctors in their role as prescribers of the drugs used to cause death. Dignitas term initial approval as a provisional green light, which enables the applicant to proceed to schedule a date and time for an assisted death if they so wish. This scheduling does not have to take place immediately, but if left for a prolonged time, it may require re-submitting more contemporaneously verified administrative documents. The final act of death usually occurs at a private residence utilized by the Swiss AD association within office hours to facilitate administrative procedures following death (Dignitas, 2023c; Eternal Spirit, 2023; Pegasos, 2023c).

Assistance from others can be provided to make the administration of the drugs as easy as possible. However, the Swiss regulatory framework requires the applicant to self-administer (AS) the drugs/perform the final causal act (e.g., the final flick/press of a switch on an intravenous drip, which can be prepared and inserted wholly by another). Voluntary euthanasia/administration of life-ending drugs by another is prohibited within Swiss criminal law. Death follows, either by ingestion (following anti-emetics to mitigate the chance of vomiting), typically involving the need to drink 50mls of (apparently bitter-tasting) barbiturate liquid, or by intravenous administration (usually containing barbiturates in doses more than ten times standard therapeutic dosages). This final process is filmed (as legal evidence) and includes a recorded last check that the individual understands what would happen if they chose to self-administer the drugs. Death is subsequently reported to the local authorities for investigation, with a Swiss death certificate issued locally if no concerns are identified (Dignitas, 2023c; Eternal Spirit, 2023; Pegasos, 2023c).

2.4 Swiss imprecision

The existence of Swiss associations is made possible by Article 115 of the Swiss Federal Criminal Code, which does in fact criminalize the intentional assisting of suicide but *only* when the assistant acts out of a selfish or self-serving motive (e.g., financial reward).⁵ Breaking this law is punishable by a maximum sentence of five years imprisonment or a financial penalty. Voluntary euthanasia (VE) is criminalized as homicide by Article 114. As Huxtable (2010, para. 3) points out succinctly (regarding English and Welsh criminal law but transferable to Article 114), "mercy killing is still killing".⁶ Additionally, Article 117 criminalizes the causing of the death of another through negligence or recklessness. For Swiss AD practices, this has been taken to mean that the individual must have mental capacity at the time of death (Black, 2014). Providing AD to someone without mental capacity is a crime punishable by a maximum of three years imprisonment or a monetary penalty. This requirement contrasts with jurisdictions such as The Netherlands that allow VE/practitioner administration, including via surrogate decision-making at the time of death through advance decisions. As my study focuses on the experiences of those seeking an AD in Switzerland, considerations surrounding surrogate decision-making and mental capacity lay outside the scope of my thesis. Mental capacity at the time of death should be inferred as a requisite component in my usage and conceptualization of AD.⁷

What distinguishes Swiss criminal law from other permissive jurisdictions is how AD is enabled via its omission from criminal codes⁸ when compared to other jurisdictions that have enacted specific

⁵ English is not an official Swiss language, so all references to Swiss law should be taken as explanatory only. Selfish motives are undefined but has origins in assistors (d) somehow gaining out of the individual's (p) death (e.g., inheritance) (Sperling, 2019). Subsequently, the application charge levied on applicants for an assisted death covers the association's working costs on a not-for-profit basis.

⁶ This point highlights the lack of clarity in utilizing AD as an umbrella term, as Switzerland only allows for assisted suicide (AS)/self-administration.

⁷ *Mental capacity* is a term with specific legal meanings in different jurisdictions, including the UK. These intricacies also lay outside the scope of my thesis. In short, I refer to mental capacity as the cognitive and communicative ability to make decisions for oneself.

⁸ Andorno (2013) highlights that this is likely an unintended consequence, as those drafting Article 115 in the 1930s did not envisage facilitating contemporary AD practices.

permissive legislation for AD. AD in Switzerland is not a legal right, merely non-punishable⁹. To recap, Article 115 *only* criminalizes assistance if the assistor acts out of a selfish motive. Therefore, if assistance is provided with an altruistic intent and provided on a not-for-profit basis, assistance is not legally proscribed. However, Swiss federal narcotic laws regulating the prescribing of the barbiturates used in Swiss AD practices complicate the matter further (Black, 2014), specifically regarding eligibility.

In 2017, the vice-president of the Swiss AD association EXIT (Dr Pierre Beck) prescribed barbiturates to an otherwise healthy 86-year-old woman so that she could die alongside her terminally ill husband. He was charged and subsequently cleared of transgressing federal narcotic laws at Cantonal level, a ruling that has been referred to the Federal Supreme Court by prosecutors (swissinfo.ch, 2023). Crucially, Article 11 of the federal law on narcotics stipulates that a doctor can only prescribe and dispense narcotics in accordance with 'medical science' (Black, 2014). Black (2014) comments that it is the ethical guidance produced by a non-governmental body, the Swiss Academy of Medical Sciences (SAMS), which is afforded a level of respect almost akin to legislation about what is and what is not deemed as appropriate professional Swiss AD practice and thus what defines 'medical science'. SAMS guidance has evolved over many years, becoming ever more detailed as to what it defines as constituting appropriate professional practice. From its very earliest iterations though it has always stipulated a restricted eligibility criteria for access to AD, originally stating that "the patient's disease justifies the assumption that he is approaching the end of life" (SAMS, 2004, p. 6; SAMS, 2013, p. 9). Current guidance now states clearly that providing an assisted death to those that have a lack of underlying medical condition "is not ethically justifiable" (SAMS, 2021, p. 24). Those with unbearable suffering must have this "substantiated by an appropriate diagnosis and prognosis" as the source of the intolerability (SAMS, 2021, p. 23). It is the role of this guidance, originating from a non-governmental body (and not legislation), that the Swiss Federal Supreme Court may decide to consider regarding the case of Dr Pierre Beck.

What is essential to take away from the case of Dr Pierre Beck is how vital the applicant's (ill) health status is because of how it functions to legitimize a compassionate motivation for assistance contra selfish motives (as per Article 115) whilst also mitigating SAMS guidance. It is these details that provide the Swiss regulatory origins for the requirement for UK citizens to provide medical documentation. For what is also omitted from Swiss federal laws are (national) residency requirements that restrict eligibility to only Swiss residents. These restrictions are something that all other jurisdictions have in

⁹ As Coggon (2006, p. 219) comments (regarding English and Welsh law but relevant to this aspect of the Swiss law), "...being allowed to do something is not always equivalent to having a right to do it".

some form (Sperling, 2019), and it is these omissions that uniquely enable the phenomenon of UK citizens seeking assisted deaths in Switzerland.

2.5 The UK's regulatory framework

Following the Swiss requirement for medical documentation as part of the AD application process, I have used the professional regulation of doctors by the General Medical Council (GMC) as the jurisdiction framing my thesis. In the first instance this is a pragmatic decision, considering the underlying conditions applicants cite for their suffering this documentation are largely requested from and produced by doctors. As such, the regulatory and professional bodies that govern doctors have created the main bulk of the regulatory literature. In other jurisdictions, it has also been shown that doctors take a central role in requests for AD. For example, in The Netherlands, general practitioners (GPs) receive around 80% of requests for an assisted death (Onwuteaka-Philipsen et al., 2010), with 93% of all practitioner-administered assisted deaths performed by GPs in 2015 (Kouwenhoven et al., 2018). These points are not to say that only doctors receive requests or that doctors' experiences should take precedence. On the contrary, nurses have been shown to occupy a crucial role in AD practices as the first to receive requests, contribute to multi-disciplinary decision-making, and perform the role of the practitioner administering the drugs (De Beer, Gastmans and Dierckx de Casterle, 2005; Elmore, Wright and Paradis, 2016). Instead, a requirement for brevity means that I cannot consider each profession impacted by requests for medical documentation. Therefore, the issues raised by my focus on doctors and GMC regulation should be seen as an exemplar for all UK-based HCPs.¹⁰

While my choice of regulatory jurisdiction is primarily pragmatic, it is not without complexities highly pertinent to the permissive proposals that are likely to be voted on in 2024 within Scotland and the Crown dependencies of Jersey and the Isle of Man. These complexities begin at the constitutional level of the political union that makes up the United Kingdom of Great Britain and Northern Ireland. While the UK Parliament in the Palace of Westminster retains legislative sovereignty regarding certain critical functions known as reserved matters (such as military defence), individual nations within the union are granted powers to legislate over other areas (known as devolved matters). These distinctions are important because although data rights and the regulation of medical practitioners are reserved

¹⁰ Many HCPs can provide the documentation required for Swiss AD associations, as no professional standards exist regarding authorship. Of note, the Royal College of Nursing has guidance entitled *When someone asks for your assistance to die* (<https://www.rcn.org.uk/Professional-Development/publications/pub-005822>).

matters legislated for across the entirety of the UK by the UK Parliament, criminal justice is a devolved matter. As such, the Westminster Parliament legislates criminal law for England and Wales (as one legal jurisdiction), the Scottish Parliament legislates criminal law for Scotland, and the Stormont Parliament legislates likewise for Northern Ireland. However, the General Medical Council (GMC), the statutory body empowered by the *Medical Act 1983* to regulate doctors, regulates across all these criminal jurisdictions. The Crown Dependencies are self-governing but also legislate for the GMC to regulate doctors who work within their borders.

Criminal law regulating assistance varies between the separate criminal jurisdictions of the UK and is notably more developed within England and Wales. In Scotland, AD is likely to be criminally prohibited under offences of murder or culpable homicide.¹¹ Notably, Lord Carloway in *The Court of Session* seemed to clarify the issue of assisting people to travel to Switzerland for an assisted death:

"...acts which do not amount to an immediate and direct cause are not criminal. Such acts, including taking persons to places where they may commit, or seek assistance to commit, suicide,...do not, in a legal sense, cause the death, even if that death was predicted as the likely outcome of the visit"¹²

¹¹ *MacAngus v HM Advocate* LIG (Hamilton) at Para [42]. Referenced in *Assisted Dying for Terminally Ill Adults (Scotland) Bill* at footnote 16 (<https://www.parliament.scot/-/media/files/legislation/proposed-members-bills/assisted-dying-for-terminally-ill-adults-scotland-consultation-2021-final.pdf>).

¹² *Ross v Lord Advocate* (2016) CSIH 12 at Para [31] (<https://www.scotcourts.gov.uk/search-judgments/judgment?id=363108a7-8980-69d2-b500-ff0000d74aa7>).

Within England and Wales AD is governed by the *Suicide Act 1961*. Section 1 of the *Suicide Act 1961* decriminalized the specific action of ending one's own life, yet it is Section 2 that is most relevant, creating an offence of complicity in another's suicide¹³:

"2 Criminal liability for complicity in another's suicide.

(1) A person ("D") commits an offence if -

a) D does an act capable of encouraging or assisting the suicide or attempted suicide of another person, and

(b) D's act was intended to encourage or assist suicide or an attempt at suicide.

(1A) The person referred to in subsection (1)(a) need not be a specific person (or class of persons) known to, or identified by, D.

(1B) D may commit an offence under this section whether or not a suicide, or an attempt at suicide, occurs."

This offence carries a maximum custodial sentence of 14 years in prison. Huxtable (2007) provides examples that have been deemed criminally culpable, such as (d) helping to secure a plastic bag over the head of an individual (p), (d) attaching a hose to an exhaust pipe of a car (in which an individual already sat) and (d) holding a shotgun in an individual's (p) mouth while the trigger was pulled by the individual (p). A prosecutorial policy provided by the Crown Prosecution Service (CPS) guides prosecution decisions, containing 16 factors that tend toward prosecution and six that tend against prosecution (Appendix Two).

Mullock (2012, p. 17) argues that these factors have created an ambiguous space between two extremes of "explicitly allowing and robustly prohibiting". On the one hand, these factors seem to confirm that those assisting another to go to Switzerland for AD will, on balance, not face prosecution, as the factors usually engaged are those that tend against prosecution (Huxtable, 2009; Mullock, 2010;

¹³ Section 13 of the *Criminal Justice Act (Northern Ireland) 1966* creates a similar offence (with similar wording) in Northern Ireland. I will utilize English and Welsh law as an exemplar of Northern Irish law because of these similarities (including subsequent prosecution guidelines).

Mullock, 2012; Rehmann-Sutter and Hagger, 2011). However, as Huxtable (2009) highlights, a legal trap remains as there is no statutory guarantee for non-prosecution in these cases because assistance remains illegal.

One of the factors surrounding assistance which tends towards prosecution, factor 43(14), is highly relevant to my thesis:

“...[T]he suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional, a professional carer [whether for payment or not], or as a person in authority, such as a prison officer, **and the victim was in his or her care**[1]”

Footnote [1]: “For the avoidance of doubt the words "and the victim was in his or her care" qualify all of the preceding parts of this paragraph [43.14]. This factor does not apply merely because someone was acting in a capacity described within it: it applies only where there was, in addition, a relationship of care between the suspect and the victims such that it will be necessary to consider whether the suspect may have exerted some influence on the victim.” (Director of Public Prosecutions, 2014)

In naming HCPs, this factor creates a heightened sense of regulatory risk for HCPs and creates subtle tensions with data protection rights that HCPs must balance in practice. As Mullock (2010) comments, a doctor who refuses to release copies of medical records preventing a person from making an informed choice could be contravening data protection legislation. It is to these subtle tensions regarding the provision of medical documentation that I now turn to.

2.6 Data rights, data wrongs

Pre-2018, *The Data Protection Act 1998* gave individuals the right to see the personal information about them held by an organization. Making a request to access this information was (and still is) termed a Subject Access Request (SAR). These requests were liable for a fee and must have been made in writing to the organization that held them. The fees for a SAR depended on what was requested

but ranged from £10 for copies of electronic records up to a maximum of £50 for paper records. Crucially, this was a positive right; when requesting, a reason did not have to be given.

Countering this was a list of caveats that limited this right, contained within Article 5 (1) of the *Subject Access Modification (Health) Order 2000*. This article exempted access to medical documentation if it “would be likely to cause serious harm to the physical or mental health or condition of the data subject or any other person”. The person making this assessment was the HCP who was most appropriate to answer whether Article 5(1) applied. What constituted an assessment of the degree of likelihood and what serious harm meant was not detailed.

In May 2018, the *Data Protection Act 2018* was enacted, which contained some minor differences from the 1998 Act¹⁴: abolishing fees for a SAR, a reduced timeframe for organizations to respond, and the requirement to make data available in the mode it was requested (e.g., if requested electronically, it should be available electronically). Since 2015, there has been a limited ability to see online records but this has now been supplanted by an automatic right to see the general practice record prospectively and a low threshold for granting retrospective access (within England and Wales) (NHS Digital, 2023), part of a pan-national strategic drive to increase electronic access and the sharing of information including health records.

Limitations or exemptions to access are almost identical to Article 5(1) of *The Data Protection (Subject Access Modification) (Health) Order 2000* seen above. Contained in Schedule 3, Part 2 of the *Data Protection Act 2018*, these have been formalized into a named assessment entitled the serious harm test. Again, there is no guidance on what constitutes the workings of this assessment. However, at the very least, it creates a duty upon an HCP to articulate their reasoning as to why withholding documentation meets this serious harm threshold. It is this power to refuse access that first identifies an asymmetry in the power held between an applicant and HCP within encounters involving the seeking of medical documentation (in this case legislated for by the state). If a person is refused access to their medical records, they are entitled to appeal to the Information Commissioner’s Office (ICO), the non-departmental public body tasked with upholding an individual’s information rights. Again, it would seem incumbent on the ICO to check that the HCP has set out their reasoning as to why denying an individual’s request meets the serious harm test.

¹⁴ This revised act incorporated and worked alongside the *European General Data Protection Regulation* (now the *UK General Data Protection Regulation* following the UK's exit from the European Union).

It is the right created by the *Data Protection Act 1998* and subsequently the *Data Protection Act 2018* for individuals to access information regarding their health and treatment that causes a subtle tension with factor 43(14) of the CPS prosecutorial guidelines that I quoted at the end of section 2.5. To explain this further, I will utilize the guidance created by the GMC to help professionals navigate these tensions.

To begin with, the most visible advice the GMC gives to doctors is on its website regarding patients seeking advice or information about AD, and states:

“Doctors should:

- a) be prepared to listen and to discuss the reasons for the patient’s request
- b) limit any advice or information in response, to:
 - i) an explanation that it is a criminal offence for anyone to encourage or assist a person to commit or attempt suicide, and
 - ii) objective advice about the lawful clinical options (such as sedation and other palliative care) which would be available if a patient were to reach a settled decision to kill them self” (GMC, 2022, p. 2)

However, it is a document entitled *Guidance for the investigation committee and case examiners when considering allegations about a doctor’s involvement in encouraging or assisting suicide* that contains details about the provision of medical documentation. This guidance document is intended for those investigating a doctor for a potential breach of practice. It takes a similar approach to the CPS guidelines by listing factors that tend towards or away from a breach of professional conduct. Section 20c states that:

“...[W]riting reports knowing, or having reasonable suspicion, that the reports will be used to enable the person to obtain encouragement or assistance in committing suicide...may raise a question of impaired fitness to practise” (GMC, 2014).

This section provides a helpful and clear delineation: writing a report could be liable to professional sanction and stems from the uncertainty created by factor 43(14) of the CPS prosecutorial policy. The purposeful commission of a medical report could be deemed a criminally culpable act (equally, it may not be, but it would be weighed up with all the other factors of the case). GMC advice can therefore be seen as ensuring doctors practice within the law¹⁵.

While section 20c is helpful, it concerns commissioning a new piece of documentation that only exists once requested. This still leaves the issue of SARs and access to/copies of pre-existing medical records or other documentation. Section 23 of this same guidance addresses this:

23 "Some actions related to a person's decision to, or ability to, commit suicide are lawful, or will be too distant from the encouragement or assistance to raise a question about a doctor's fitness to practise. These include but are not limited to...
...providing access to a patient's records where a subject access request has been made (in accordance with the terms of the Data Protection Act 1998)" (GMC, 2014)

On the face of it, this also seems helpful. However, there is a subtle, yet important, omission in comparison to the wording of section 20c regarding the commission of medical reports. This omission is about "knowing or having reasonable suspicion" about what the medical records/documents are to be used for. I asked the GMC to clarify this detail, which they did:

"We have had legal advice to the effect that a doctor's compliance with a subject access request, even if they knew the reason for that request, would be too far removed from the act of suicide to constitute encouragement or assistance"
(Personal communication, 2017)

¹⁵ In addition, as the regulator of medical practice, the GMC can set its own boundaries regarding what it defines as appropriate professional practice.

To help clarify this point to a wider audience, I have already stated in a journal article that “even if a patient requests copies of medical records with the stated intention of using them for an assisted death abroad and the doctor then complies with this request, this is deemed an action too distant to raise a question about a doctor’s fitness to practise” (Teed, 2017).¹⁶ What becomes clear from this guidance is a demarcation between the types of documentation requested. This demarcation lies in the difference between medical records, which already exist, versus medical reports which involve a specific act of commission. This subtle demarcation highlights the detail in balancing competing tensions between factor 43(14) of the CPS guidelines on assistance and an individual’s data rights in practice. What this detail also goes to show is how GMC guidance, regulating doctors across all nations of the UK, is in fact mainly influenced by English and Welsh law. The further importance of this point is that the GMC will likely face further complexities that will need further clarification *if* permissive legislation is enacted in Scotland or the Crown Dependencies in 2024.

2.7 Summary

In this chapter, I have addressed the terminological choices I have made in using *AD* as an umbrella term as consistent with understanding *AD* as a process (instead of focusing on the final act that causes death). I then introduced what Swiss *AD* involves and highlighted the regulatory origins for the requirement for medical documentation within an *AD* application: the need to comply with Swiss criminal law and federal laws surrounding narcotics. Following this, I identified the complexity involved in defining the relevant UK regulatory framework. Separate criminal jurisdictions of individual nations make up the political union of the UK, whereas the professional regulator of doctors (which I define as the jurisdiction of my study) regulates across them all.

A subtle tension exists between English and Welsh criminal law (that can be seen to influence GMC guidance) and data protection regulations. CPS prosecution guidelines create a heightened sense of

¹⁶ Previous British Medical Association (BMA) guidance mirrored GMC guidance, originally not mentioning *AD*. Updated in 2019, it is now more explicit in stating that a doctor “should not...write medical reports specifically to facilitate assisted suicide abroad” but is “obliged” to provide medical records “regardless of whether the doctor knows or suspects that the medical records may be used abroad for assisted dying” (BMA, 2019, p. 4). In similarity to the Royal College of Nursing (RCN), it also warns against closing down communication, introducing personal beliefs, and the prospect of professional abandonment (RCN, 2016; BMA, 2019).

legal risk for HCPs as they are uniquely named in factor 43(14) that tends towards prosecution. Yet, it is in the detail of professional guidance from the GMC where an importance is placed between the access to medical records as a data right of an individual vs the commission of a medical report as demarcating potential professional (+/- possible criminal) transgression.

In providing the relevant regulatory background to the setting for my thesis, I have identified the tensions and risks faced by HCPs in practice. In doing so, I have also identified a power differential inherent in this setting between applicants and HCPs, as HCPs are empowered by the state with the ability to deny access to documentation (with oversight from the ICO). It is to this issue of the importance of the power and influence that HCPs have within a clinical encounter that I will return to in the next chapter which discusses AD as a discursive process.

3 Assistance talk

3.1 Introduction

In the previous chapter, I identified the setting for my thesis and the relevant regulatory background, revealing subtle tensions between prosecutorial guidelines surrounding assistance and an individual's data rights. In this chapter, I continue to frame the background to my study by reviewing the literature on the phenomenon of seeking the option of an assisted death.

I begin by introducing the literature on the wish to hasten death (WTHD), highlighting the key motivations and intentions behind requests for assisted dying (AD). In doing so, I identify an essential conceptual understanding: that a request for AD does not necessarily lead to an assisted death nor necessarily means an intention to die. Subsequently, I address the relational context of a WTHD and why the framing of AD as a discursive process is an important area of study. I finish by highlighting the comparatively sparse literature regarding experiences within the UK and present my research question.

3.2 *The Wish To Hasten Death*

Much like the terminological variety surrounding the term *AD*, the terms used to capture the phenomenon of seeking the option of an assisted death are just as varied: *the wish to die*, *the desire to die*, *the desire to hasten death*, *the desire for death*, and the *wish to hasten death* (the WTHD). I shall utilize the WTHD, as used in the most recent meta-syntheses (Rodríguez-Prat et al., 2017) but it is important to highlight that these terms are themselves highly debated and can also obfuscate what is being referred to¹⁷.

Overall, assisted deaths constitute a minority of all deaths recorded each year in jurisdictions with permissive legislation: Oregon 0.6% (Oregon Health Authority, 2023), Switzerland 2.1% (Swiss Federal Statistics Office, 2023), Canada 4.1% (Health Canada, 2023), Netherlands 5.1% (RERC, 2023). Studies attempting to quantify the number of people with an advanced illness who hold a WTHD in societies around the world have produced wildly varying ranges, from 1.5-55%. Multiple rating scales have been employed in an attempt to quantify the clinical and existential parameters related to a WTHD, including mood, existential distress, and intensity of disease symptoms. The two most established are

¹⁷ For example, the WTHD is generally not considered to be synonymous with 'the wish to die' but a subtype of the latter (Schroepfer, 2006).

versions of the *Schedule of Attitudes Towards Hastened Death* (a patient self-reported questionnaire) or the *Desire for Death Rating Scale* (a healthcare professional led semi-structured discussion). These validated scales suggest the range is more likely to lie somewhere between 5-28% (Chochinov and Wilson, 1995; Price et al., 2011; Wilson et al., 2014; Bellido-Pérez et al., 2016; Belar et al., 2021), with both skewing towards trying to identify those with the highest levels of a WTHD.

A well-established foundation of qualitative literature addresses what the WTHD encompasses, with four systematic syntheses published since 2006 (Hudson et al., 2006; Hendry et al., 2012; Monforte-Royo et al., 2012; Rodríguez-Prat et al., 2017). Most studies on the WTHD have been conducted within Western Europe and North America, with similarities seen across multiple jurisdictions despite contrasting regulatory frameworks, whether permissive or prohibitive. Specifically, Pestinger et al. (2015) found similarities in motivations for requests comparable between a permissive jurisdiction (Switzerland) and one where AD was prohibited (Germany). Likewise, Vorhees et al. (2014) found similarities regarding the experiences of healthcare professionals (HCPs) when receiving and responding to requests for AD between jurisdictions that legislated permissively (The Netherlands and Oregon, USA) and jurisdictions that legislate prohibitively (multiple other states of the USA).

The overarching theme Rodríguez-Prat et al. (2017) presented within the most recent meta-synthesis describes reactive and agential experiences of an individual's suffering as central to understanding a WTHD. In a previous meta-synthesis by Monforte-Royo et al. (2012), control had been an additional overarching theme, something I will return to shortly in the next sub-section. The suffering described within the meta-syntheses comprises complex and often contradictory physical, psychological, existential, and social experiences of living with an advanced illness. The authors of the meta-synthesis present a typology of the WTHD primarily based on one interpretive phenomenological study of 30 terminally ill Swiss people by Ohnsorge, Gudat and Rehmann-Sutter (2014). I find the typology offered in this original study (figure one) more helpful than the meta-synthesis in highlighting three components of the WTHD: possible motivations behind the WTHD, possible intentions of requesting AD, and the relational nature of requesting AD.

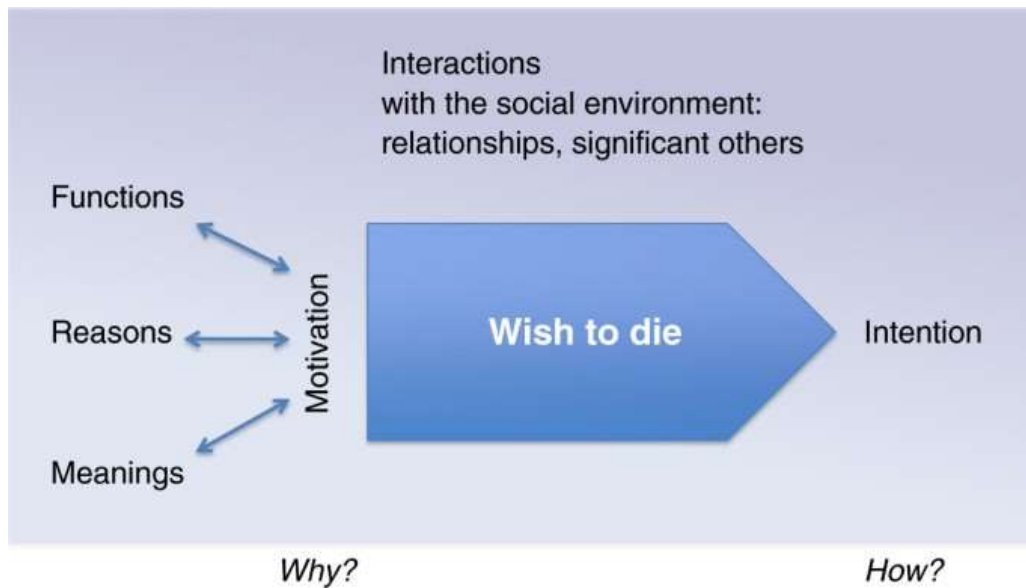


Figure 1. *The desire for death: motivations, intentions, and their social setting.*

(Ohnsorge, Gudat and Rehmann-Sutter, 2014)

The focus of most of the WTHD literature has been on attempting to identify and understand the potential motivations as to why someone might hold a WTHD. A loss of self-identity associated with advanced illness is highlighted as central, encompassing physical, social and psychological factors (Lavery et al., 2001; Coyle and Sculco, 2004; Mak and Elwyn, 2005; Pearlman et al., 2005; Nissim, Gagliese and Rodin, 2009; Dees et al., 2011; Ohnsorge, Gudat and Rehmann-Suter, 2014; Pestinger et al., 2015; Richards, 2016; Young et al., 2021). All studies included in the meta-synthesis mention physical symptoms, referring mainly to the unwanted experiences of illness (such as pain, shortness of breath, and incontinence) and a loss of function (both cognitively and physically). These can lead to a perceived loss of a role within social structures or an inability to carry out daily activities (that previously brought joy) (Rodriguez-Pratt et al., 2019). Chochinov (2023) encompasses all these factors by designating this loss of self-identity as a “fractured personhood”. Linking to Becker’s (1973) theory of death denial, Coyle (2004) describe loss of identity as an “existential slap.” The existential slap describes the sudden and unavoidable awareness of our own mortality and the potential for death (something ordinarily kept out of everyday consciousness) as a psychological response that can accompany a diagnosis of advanced illness. As such, fear also looms large in the WTHD and centers on the uncertainty of the future, particularly of potential symptoms (or their recurrence) in the context of disease progression over time.

3.3 The *option* of assisted dying

Time is central to understanding AD as a discursive process as the WTHD is not a static phenomenon; a WTHD can change or fluctuate over time (Emanuel, Fairclough and Emanuel, 2000; Jansen-van der Weide, Onwuteaka-Philipsen and van der Wal, 2005; Marcoux et al., 2005; Hudson et al., 2006; Wilson et al., 2007; Rosenfeld et al., 2014). Rosenfeld et al. (2014) provide a helpful illustration of this (figure two) identifying four trajectories of a WTHD, presenting these in graphical format comparing *Schedule of Attitudes Towards Hastened Death* (SAHD) scores (the higher the number, the more strongly held the desire) over time:

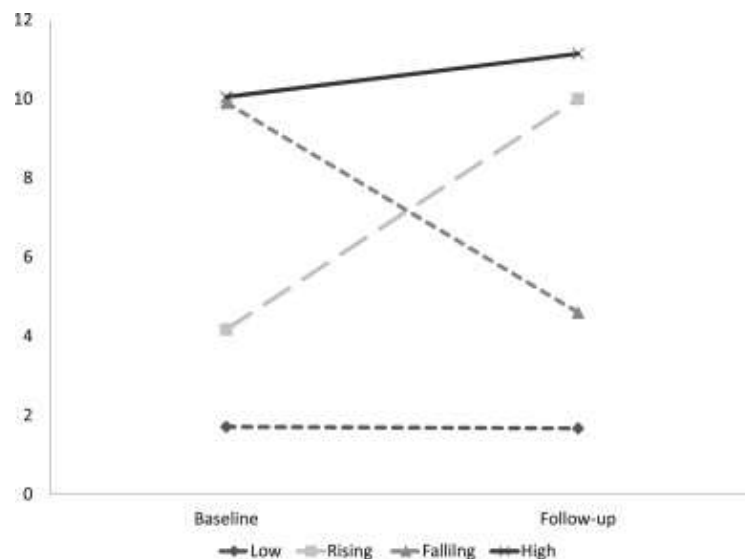


Figure 2. SAHD scores and WTHD trajectories (Rosenfeld et al, 2014)

These trajectories suggest that the WTHD can be a highly variable, ambiguous, and individual phenomenon. Crucially, requesting an assisted death does not necessarily equal a desire to die or actually receive an assisted death (Norwood, 2020; Baler et al., 2021). As such, applicants do not always progress with an AD application to receive an assisted death; numerous falling trajectories of a WTHD are seen in the literature. For example, a review of death certificates in The Netherlands found that only a third of those who initially requested AD received an assisted death (Onwuteaka-Philipsen et al., 2010). Figure three (below), taken from a single study conducted in The Netherlands, illustrates this declining trend in the numbers of applicants (represented by the letter P on the vertical Y axis) progressing through the stages of an AD process:

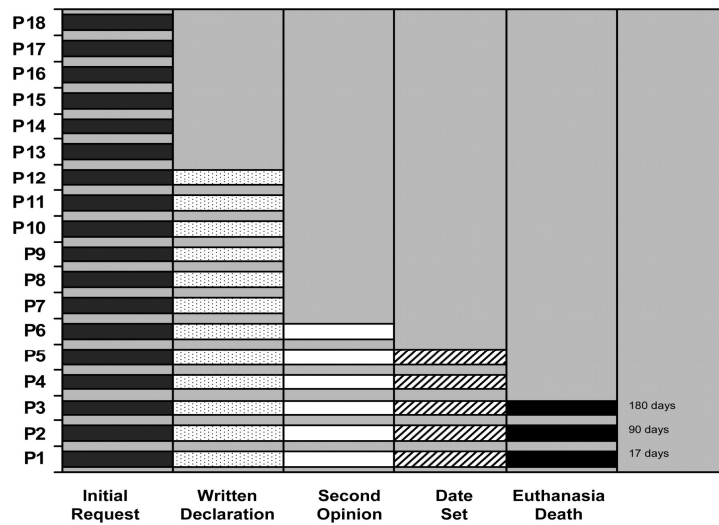


Figure 3. Five stages of an AD process (Norwood, Kimsma and Battin, 2009)

While some applicants may die as they progress through the process, a declining trend in the WTHD highlights that some intentions behind a request can be more hypothetical. One theme from the Rodríguez-Prat et al. (2017) meta-synthesis on the WTHD is highly pertinent to the falling trajectory seen in the graph above yet seems somewhat paradoxical when discussing the WTHD: the will to live (Coyle and Sculco, 2004; Pearlman et al., 2005; Mak and Elwyn, 2005; Dees et al., 2011; Ohnsorge, Gudat and Rehmann-Sutter, 2014; Rodríguez-Prat et al., 2017; Young et al., 2021). A request for AD can be a psychological safety net/insurance policy for a feared future: that if suffering becomes unbearable, AD may be desirable (Coyle and Sculco, 2004; Richards, 2016; Monforte-Royo et al., 2012). Monforte-Royo et al. (2012) described this in an earlier meta-synthesis on the WTHD as akin “to having an ace up one’s sleeve, just in case” (p.12), as way of reaffirming their autonomy and ability to make their own decisions. Monforte-Royo et al. (2012) link this desire for control to the importance seen throughout a patient’s experience of healthcare where autonomy and capacity for decision-making is/has always been always central. It is for this reason that control was an additional overarching theme in their meta-synthesis alongside suffering, seen in figure four below. Interestingly, Monforte-Royo et al. (2012) also note that as a result of gaining this control, some felt more able to tolerate present and future pain and uncertainty. Gandsman (2018) goes further to argue that having the option of AD means individuals may not feel compelled to live and suffer but instead choose to live. The option to die, therefore, interpolates a choice to live, which can be an attempt to reassert control and agency over life and death and become a way of enduring the unendurable (suffering) (Coyle and Sculco, 2004; Rodriguez-Pratt et al., 2016; Richards, 2016; Gandsman, 2018; Young, 2021).

WISH TO HASTEN DEATH IN PATIENTS WITH CHRONIC OR ADVANCED ILLNESS

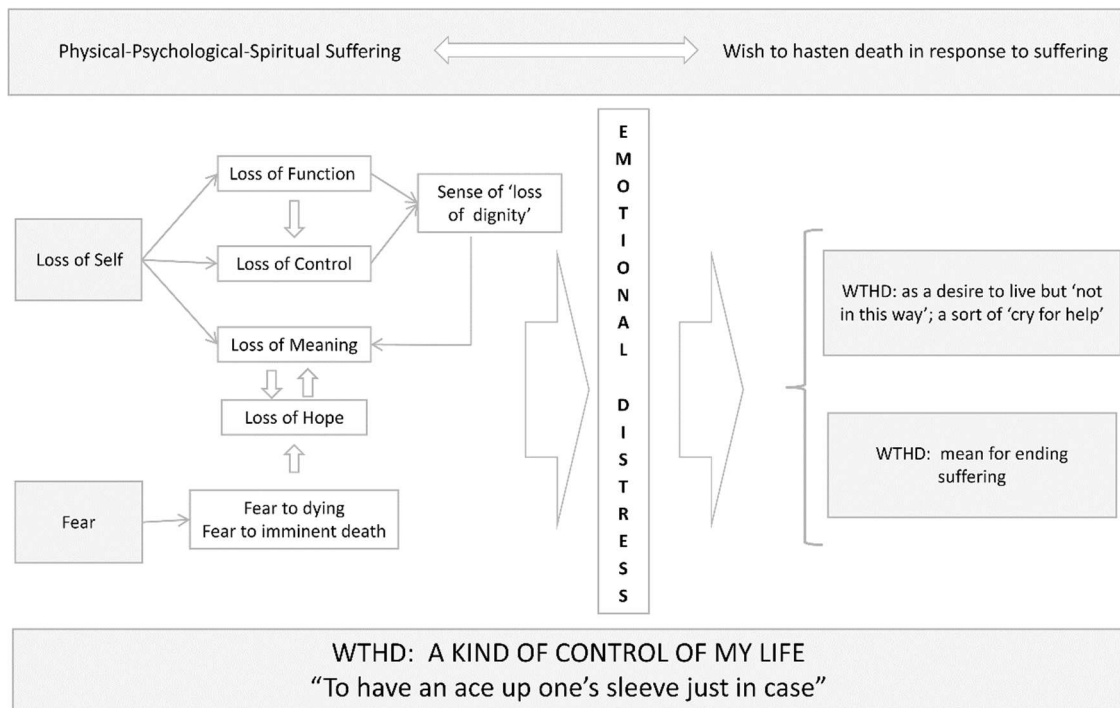


Figure 4. Explanatory model of WTHD (Monforte-Royo et al., 2012)

Canadian statistics reveal that 81% of all those who completed a written application for AD in 2022 received an assisted death (Health Canada, 2023). In Oregon (USA), of the 3280 people who received a prescription for life-ending drugs since the introduction of permissive legislation in 1997, 66% have died by ingesting them (Oregon Health Authority, 2023). These statistics highlight that the WTHD can also involve purposefully choosing death (Rurup et al., 2011; Ohnsorge, Gudat and Rehmann-Sutter, 2014; Richards, 2016; 2019; Young, 2020). These more purposeful intentions have led to a newer and lesser-researched aesthetics of (assisted) dying, referring to the individual preferences and rituals of AD, something Buchbinder (2018) refers to as the choreographing of death. This choreographing of (assisted) death means that people can now plan, organize, and even schedule the time of their death. Magnusson (2002) gives examples of “pre-death wakes”, parties where the dying individuals plan the menus, decorations, music, and guest list of who is to be present (including possibly at the time of death itself). Others described by Magnusson were more modest and intimate, such as dying with a partner present and a glass of champagne.

What seems vital to conclude from this literature is how applicants are (at the very least) highlighting the importance of identity, agency, and control to them as individuals when disclosing a WTHD.

However, this conclusion only provides a limited understanding of the literature on the WTHD, which also comprises a relational aspect (figure one, page 40). It is to the relational aspect of a WTHD that I now turn to, and specifically the discursive process at the heart of requesting assistance from another.

3.4 Assistance talk

I will term the discursive process of AD *assistance talk*, modifying descriptive terms utilized by Magnusson (2002) (suicide talk) and Norwood (2020) (euthanasia talk) to incorporate my umbrella usage of AD. The discursive relationship typically described in the literature is one of a patient-HCP dyad, with the experiences and perspectives of HCPs dominating those of applicants¹⁹ (Elmore et al., 2018; Fujioka et al., 2018; Brooks, 2019; Patel et al., 2020; Ward et al., 2021; Byrnes, Ross and Murphy, 2022; Sandham et al., 2022). However, family/friends/carers/loved ones can also be heavily integrated within assistance talk, even performing active roles in influencing or dissuading decisions about requests, including facilitating applications administratively (Starks et al., 2007; Buchbinder, 2018; Gamondi et al., 2018; Norwood, 2020). As Buchbinder et al. (2018, p. 936) state, AD “is often presented as a simple matter of individual choice and autonomy, yet most patients who pursue it do so with tremendous support from caregivers, who are in turn deeply implicated, socially and morally, in the process”. In contrast to HCP experiences, the experiences of family members are less explored and are rarely considered within clinical guidelines or regulatory frameworks (Gamondi et al., 2019).

Few studies focus on the experiences of disclosing a WTHD or of requesting assistance itself; those that do have studied patient-family dyads (Back et al., 2002; Arnold et al., 2004; Pearlman et al., 2005; Jansen-van de Weide et al., 2009; Norwood, Kimsma and Battin, 2009), doctor-family dyads (Snijdwind et al., 2014) and patient-doctor-family triads (Dees et al., 2012; Pasman, Willems and Onwuteaka-Philipsen, 2013; Serota et al., 2023). With all these points in mind, I take a patient-HCP-loved one (whether family or friend) triad as a more appropriate description of those involved in assistance talk.

Norwood (2020) draws on the works of Foucault to describe assistance talk as a fluid process where those involved attempt to navigate the complexities and uncertainties of a WTHD together. Crucially, assistance talk does not occur within a cultural vacuum but is “constructed by and among people”

¹⁹ Brooks (2019) comments that studies of HCP experiences are themselves typically dominated by those of doctors above other professions.

where possible meanings and intentions of a request are formed and understood by all those involved, including the applicants themselves. Haning (2019) characterizes this as a kind of agentic displacement, where personal agency becomes dispersed amongst a range of moral stakeholders. These stakeholders can be seen at an individual level (such as the patient/HCP/loved one triad) and at the societal level, including entities such as medical institutions, professional regulatory bodies, or the state itself.

Young et al. (2021) subsequently identify an illusion of control inherent to seeking assistance from another, which can act to reinforce power relations within society. While applicants may seek greater control (and even propose a distinctly epistemic contestation to medical knowledge, authority, and practice) this is partially illusory as ultimate control still resides with the doctor as gatekeeper, who can decline or approve their request. Crucially, this gatekeeping role may not always be welcomed by HCPs, with many reluctant to adopt the role (Buchbinder, 2021). Some HCPs report an increased emotional burden and a sense of legal scrutiny and risk following the adoption of this role (Haverkate et al., 2001; Van Marwijk et al., 2007; Otte et al., 2016; Patel et al., 2020; Variath et al., 2020; Byrnes, Ross and Murphy, 2022), congruent with the experiences of family members and carers of those seeking AD (Starks et al., 2007; Snijdewind et al., 2014; Variath et al., 2020; Gamondi et al., 2019). Specifically, HCPs may view AD as being in direct conflict with their own professional identity or personal values (Otte et al., 2016; Patel et al., 2019; Variath et al., 2020; Byrnes, Ross and Murphy, 2022; Bustin et al., 2023).²⁰

It is these distinctly relational understandings of AD that make assistance talk an important topic to study. Ethical considerations surrounding assistance talk seem largely consequentialist in orientation and focus on the considerations surrounding who is included and who is excluded in the discursive process and the consequences of this inclusion. On the one hand, assistance talk could amplify harmful prejudices, exacerbate social inequalities, cause anxiety, and strain relationships (Vorhees et al., 2014). It is here that the power and influence an HCP has within a clinical encounter becomes relevant

²⁰ For example, hospice workers can experience requests for AD as a rejection of, or incompatible with, the values espoused by the hospice movement (Khoshnood et al., 2018; Freeman, Banner and Ward, 2021; Wright et al., 2021). Winnington (2016) suggests that seeking AD can be viewed as something deviant/bad when viewed through an authoritative palliative lens (where AD is seen as oppositional to a palliative care ethos). Balancing this are reports of the moral identity work practiced by individuals when this master narrative collides with the care of patients when values such as non-abandonment and respecting end-of-life choices overlap with AD (Wright et al., 2021).

once again. For example, in a study of the case summaries of people with intellectual disabilities (and/or autism) requesting AD in The Netherlands, Tuffrey-Wijne et al. (2018) raise the prospect of negative biases impacting on HCPs' judgements when approving AD requests. One theme in the WTHD literature surrounding motivations is highly pertinent to this: the perception of being a burden on others and the related desire to relieve others of this burden (Rodriguez-Prat et al., 2019). For some, the transition from a state of self-sufficiency to one of physical dependence can create feelings of guilt, shame, and a loss of self-esteem, which relates to the social nature of illness and the WTHD (Rehmann-Sutter, 2019; Gudat et al., 2019; Rodriguez-Prat et al., 2019). Media reports from Canada suggest that the social determinants of ill health, such as housing, loneliness, and financial concerns, can act as oppressive influences that dominate some individual's requests for AD. These experiences raise the concern that AD functions as an option but with little or no choice for some marginalized people, through offering death instead of social care. Here, inclusion in assistance talk means also offering access to social practices of ending life that did not exist before, which are cheaper and easier for the state to provide than long term social care.

On the other hand, an increasing number of studies conclude that assistance talk can function to act to have a socio-therapeutic effect. Assistance talk can create, affirm, or even strengthen social bonds and relationships, challenging the image of AD as a radically individualistic practice (Buchbinder, 2018; Norwood, 2020). Gandsman (2018) links the social function of assistance talk to an ethics of care, as assistance talk focuses on relationships and creating connections out of isolation. When patients and family report feeling able to disclose the WTHD, they also feel able to discuss multiple further concerns surrounding dying (Back et al., 2002). Kremeike et al. (2018) link these points to studies within the literature on suicide that show the discussion with another of thoughts about ending one's own life having a potentially socio-therapeutic effect²¹. Buchbinder (2018) argues similarly but from a social justice perspective, that creating new care networks is inherent to permissive medico-legal frameworks due to the requirement for applicants to continually (re)engage and strengthen ties with others (including the state) whether they like it or not. Although applicants may seek greater autonomy, many readily accept and even welcome involving others, thereby creating new (culturally acceptable) dependencies.

²¹ Empirical evidence from systematic reviews of people with cancer shows that discussing concerns around the end of life assists with psychological adjustment, promotes psychological well-being, and reduces psychosocial distress (Hudson et al., 2006).

Considerations of exclusionary practices in assistance talk are comparatively under-theorized, despite reports of the purposeful blocking of assistance talk and the active obstruction of AD applications by HCPs and family members (Back et al., 2002; Starks et al., 2007; Hales et al., 2019; Gamondi et al., 2018; Byrnes, Ross and Murphy, 2022). Magnusson (2002) argued in his study of AD practices within jurisdictions where AD is illegal that assistance talk can exist in an ‘assistance underground’, describing loose supportive networks characterized by deception and a lack of professionalism. Crucially, though, people still expect HCPs to listen and show respect for their WTHD even if AD is illegal in their jurisdiction (Pestinger et al., 2015), as it is here in the UK.

3.5 The UK context

The most relevant data on the applicability of the international literature on the WTHD to the UK context comes from a longitudinal study by Price et al. (2011) within a UK hospice setting. Using the *Desire for Death Rating Scale*, Price et al. (2011) found that 33 of 300 (11%) newly referred patients to one UK hospice reported a WTHD. As the authors note, this rate is at the lower end of the international data regarding prevalence. Of these 300, 11 (3.7%) reported higher WTHD ratings, indicating a stronger desire. These figures suggest that a WTHD in those with advanced illnesses may not be uncommon within UK palliative populations.

While no UK-based studies were included in the meta-syntheses on the WTHD, the themes developed seem consistent with those UK-based studies that touch on the WTHD (Seale and Addington-Hall, 1994; Chapple et al., 2006; Judd and Seale, 2011; Lamers and Williams, 2015; Richards, 2016). Likewise, practices of inclusion and exclusion within assistance talk also seem relevant within UK-based research. A Foucauldian-influenced study on seven older people’s perspectives on AD developed a theme of voicelessness describing the participant’s perception that HCPs were (actively) curtailing public conversations on AD by exerting their institutional power (Lamers & Williams, 2015). In another study of older people, this time on the end-of-life preferences of older lesbians and gay men in the UK, a desire for the option of AD became apparent, although the researcher had not set out to ask about it. Crucially, the participants described already having experienced living in ‘anti-normative ways’ (judged by society about how they should or should not live) which impacted on their perception of a medical authority now telling them how they should or should not die (Westwood, 2017).

Literature focusing on UK experiences of disclosing a WTHD/assistance talk is comparatively scant. In Richards’ (2016) study of those seeking the option of an assisted death in Switzerland (from the UK),

Richard's observed that she (in her capacity as the researcher) may have been the only avenue that the participants in her study had to engage in assistance talk here in the UK. However, subsequent research by the campaign group Dignity in Dying on the experiences of 19 people involved in an application for an assisted death in Switzerland revealed that disclosure of a WTHD or the seeking of an assisted death can and does occur. Crucially, disclosure was reported as occurring during the request for medical documentation, with participants reporting a variety of reactions from HCPs, from the blocking of assistance talk²² and being denied access to their medical records,²³ to HCPs purposefully supporting their applications (Riley and Heir, 2017). The request for medical documentation as a potential site for assistance talk is also confirmed by the reports of GPs contacting their medical defence organizations about fears and uncertainties in providing documentation following disclosure (Pulse, 2012).

3.6 Research question

Fears of professional (let alone criminal) sanction are crucial as they have been shown to have significant detrimental effects on the well-being of HCPs. Depression, anxiety, suicidal thoughts, shame, guilt, and anger are common reactions reported from the distress of an investigation into an HCP's practice. As a result, doctors have reported changing their practice following a fitness-to-practice investigation, including the avoidance of specific practices or patient groups, having less trust or goodwill towards their patients, and increasing their rates of tests, referrals, and prescribing as means of mitigating regulatory risk (Cunningham and Dovey, 2000; Nash, Tennant and Walton, 2004; Bourne et al., 2015; Bourne et al., 2017; Im, Tamarelli and Shen, 2023).

Back et al. (2002, p. 1263) found that fears surrounding regulatory transgression were highly relevant to assistance talk, with both applicants and HCPs colluding to avoid regulatory risk through a "don't ask, don't tell" policy. This finding seems highly relevant to an analysis of the documentation provided to Swiss AD associations within applications for an assisted death (although not just those from the

²² One participant stated: "The doctors and palliative care workers want to know how I'm handling things, but they wouldn't allow me to talk about Dignitas" (Riley and Heir, 2017, p, 24).

²³ International research also concurs with these experiences. Sperling's (2022) study of 11 Israeli citizens (AD is also illegal in Israel) who sought the option of an assisted death in Switzerland revealed that obtaining medical records was a difficult endeavour. In an extreme example, one participant was visited by the police after broaching the subject of seeking the option of AD in Switzerland with their GP.

UK) by Imhof et al. (2011). This analysis revealed that the overwhelming type of documentation provided were discharge summaries from hospital stays or copies of medical records. Interestingly, very few of these showed evidence of the applicant having disclosed their WTHD or specific plans to the HCP who had provided the documentation (Imhof et al., 2011). To the best of my knowledge, no GMC registered doctor has ever been arrested (let alone prosecuted), or professionally sanctioned, for providing medical documentation for the purposes of use in an assisted death application. Subsequently, it seems as though any fears of these consequences are somewhat disproportionate to the likelihood of these outcomes.

Considering the amount of attention AD receives, the passionate debate it stimulates, and the issues at stake, little is known about the experiences of those involved in assistance talk here in the UK. In considering the importance of the consequences of the relational setting of a WTHD, the potential for assistance talk to reinforce power relations, and the importance of fears of regulatory transgression, exploring these experiences could reveal important insights into current practices in the UK within the regulatory status quo, and their implications. As such, my study's **research question** is:

What are the experiences of those seeking or providing the medical documentation required as part of an application for an assisted death in Switzerland?

The experiences of those I seek to explore are those within the triad that I previously defined as engaged within assistance talk earlier in this chapter: prospective applicants, their family/friends/loved ones/carers, and HCPs.

3.7 Summary

In this chapter, I have reviewed the international literature on seeking the option of an assisted death and orientated my focus on AD as a discursive process. I introduced the key literature on the motivations and intentions behind a WTHD, including the reassertion of control, identity, agency, and feelings of being a burden on others. Crucially, a WTHD does not necessarily result in an assisted death, nor does a WTHD necessarily mean an intention to die. Communicative acts of disclosing a WTHD occur within distinctly social encounters (that include family members/friends/loved ones), which can help make sense of and understand what a WTHD means for the applicant.

The relational setting for the discursive process (assistance talk) reveals the potential for reinforcing social power relations and associated inclusionary and exclusionary practices that can impact all

involved. On the one hand, assistance talk can amplify harmful prejudices, exacerbate social inequalities, cause anxiety, and strain relationships. On the other hand, assistance talk can create, affirm, or even strengthen social bonds and relationships.

While the literature on the WTHD and assistance talk in the UK is scant in comparison, it suggests that the international literature is highly relevant to the UK context despite AD being illegal. Specifically, I have identified a potential setting for assistance talk that already exists in the UK when applicants request the medical documentation required as part of the AD application process. Fears of criminal or professional sanction have been shown to impact the practice of HCPs and are relevant to assistant talk in permissive jurisdictions and those where AD is illegal. These fears also inform the methodological approach I take to answer the research question, which will be the focus of the next chapter.

4 Methodology

4.1 Introduction

In the preceding chapters, I discussed the literature on seeking the option of an assisted death as a discursive process (assistance talk) and the relative lack of research on the experiences of assistance talk in the UK. I also presented the relevant regulatory background to the setting for my research question, a potential site for assistance talk in the UK: What are the experiences of those seeking, or providing, the medical documentation required as part of an application for an assisted death in Switzerland?

In this chapter, I discuss the methodological choices I have made to answer the research question. I begin by outlining the theoretical assumptions behind developing a critical reflexive thematic analysis, unpacking what I mean by *critical*. I then address the reflexive component by positioning myself and my background in relation to the research. As part of this, I highlight the importance of being a professionally regulated practicing medical doctor myself. I identify anonymity as a key research tool and describe how I utilize it within a novel study protocol that offered anonymity for participants at recruitment. I finish by describing the (thematic) analytical process utilized to develop the themes forming my findings.

4.2 Theoretical background

In the first instance, my research question seeks to explore people's experiences, indicating from the outset that I ask a distinctly qualitative question. Qualitative research is a broad term, capturing a wide variety of practices, methods, and theoretical backgrounds (Denzin and Lincoln, 2018) that focus on understanding how people "think, feel or behave in particular situations, or in relations with others" (www.ukri.org, 2022, para. 1). Braun and Clarke (2022) contend that qualitative research encompasses more than just using qualitative data, tools, or techniques, arguing that research can only be considered 'fully qualitative' if it is undertaken within a qualitative paradigm (terming this 'Big Q'). Paradigms describe the framework of beliefs and values about reality (ontology), knowledge (epistemology), and how knowledge can be obtained (methodology) that underpin and inform research (Ayton and Tsindos, 2023). Over the course of the next two subsections, I will discuss the broad philosophical assumptions and values I draw upon by taking a big Q/fully qualitative approach in developing a critical reflexive thematic analysis.

To begin, I will unpack what I mean by *critical*. Firstly, I use the term to connote a critical realist ontological foundation, posited between a positivist naïve realism (of a singular objective truth/reality independent of human existence/experience and knowable as such) and that of relativism (where truth/reality is multiple and wholly contingent upon the perspective of the observer). Positivist realism has been described as problematic because it does not recognize the social nature of knowledge (and its production), whereas a relativist ontology becomes problematic when attempting to resolve competing claims (by over-privileging perspectives rather than what is more likely to be true) (Crotty, 1998; Given, 2008; Bryman, 2016; Braun and Clarke, 2022). A positivist paradigm is more associated with my professional medical role, where causal objective truth about reality (and interventions made within it) are sought²⁴.

Instead, a critical realist ontology “broadly postulates a reality that exists independent of a researcher” while recognizing the social nature of knowledge and scientific inquiry socially embedded and mediated by human experience (Braun and Clarke, 2022, p. 169). These delineations are relevant as my study setting has a realist component concerning encounters with a binary outcome (gaining/providing or not gaining/providing medical documentation). The aims of my thesis (identified at the end of section 1.1) also imply a realist orientation in seeking to inform political and bioethical debates about what “is actually going on” (Scully, 2017, p. 195), even though I focus on social experiences. In this view, social phenomena can be seen to ‘exist’ in some form (externally to people) as they have the power to constrain or oppress, regardless of whether or not individuals recognize this (Given, 2008). An example of this is Mill’s (1997) *The Racial Contract*, which describes a racial epistemic ignorance between an officially sanctioned reality that espouses a meritocratic society (regardless of skin colour) that is divergent from the actual reality with empirical evidence to the contrary showing the reinforcing of white dominance (Congdon, 2016).

There are limits to the claims about reality that a qualitative paradigm can make, however, in only exploring some experiences of some events, articulating partial perspectives that do not and cannot give a complete account of the totality of experience. Yet, qualitative research’s aim differs from one of generalizability per se (applying from one sample to a larger group) (Lincoln and Guba, 1985). Instead, the qualitative paradigm can help understand specific recollections and experiences of specific groups of people (Mol, 2008), which then may offer knowledge that is transferable or

²⁴ Qualitative data is often used within mixed methods research. However, when used within a quantitative/positivist paradigm Braun and Clarke (2022) argue that this qualitative data is not fully qualitative (terming it ‘small q’).

applicable within these specific settings or from one setting to another if they are contextually comparable.

My epistemological foundation also complements a critical approach but sits less neatly within nomenclature. In my professional role, postpositivist approaches dominate, in which the social world (including researcher bias) is attempted to be controlled for to gain objective knowledge as far as possible. In this perspective, research outputs are viewed as mirroring reality, including social reality, as closely as possible (Bryman, 2016; Braun and Clarke, 2022). Instead, I draw upon a large body of epistemological literature that views knowledge, its production, and how it is shared, interpreted, and accepted as valid, as being contingent upon the social world and not isolated from it. Feminist scholars (amongst others such as those studying racial disparities) have been crucial in forming these understandings, articulating that researchers are socially situated themselves, and, as such, their experiences, knowledge, or research does not arise as if from out of nowhere (Scully, 2017; Harraway, 2020; Braun and Clark, 2022). A critical orientation to social situatedness is especially attuned to how knowledge is entangled with power, politics, and social relations, especially involving marginalized knowers and knowledge.

Framing assisted dying (AD) as a discursive process (assistance talk) complements this epistemological framework, having been influenced by Foucauldian insights into how knowledge and power interact to limit what can be said, by who, and what is deemed taboo (and by whom) (Norwood, 2005). Participation within collective epistemic resources can be a distinctly social process, yet social stratification allows some people to be situated so that their experiences count more (Pohlhaus, 2011). These points are relevant to the research process when considering the relationship between participants' recollections of their experiences and the researcher as an interpreter of meaning shaping knowledge production who is socially situated themselves (Braun and Clarke, 2022).

Braun and Clarke (2022) describe two approaches to interpreting meaning within a big Q approach. On the one hand, interpretation can be grounded within the meanings and life worlds that participants themselves define and understand. On the other, a researcher-led orientation interrogates participant's experiences from a researcher-directed framework. In practice, interpretation is not necessarily something that has to be as binary but, regardless, this mandates a reflexive practice by the researcher regarding how and where the research has been shaped by them (Pillow, 2003; Willig, 2017; Braun and Clarke, 2022). This reflexive practice is vital to locating the researcher and their role in shaping this research and is why I return to it throughout my thesis. This reflexive practice helps me finish unpacking what I mean by taking a critical approach and my epistemological foundations.

4.3 Locating the researcher: revisited

Most research on the wish to hasten death (WTHD) or assistance talk has taken place from a neutral perspective (Magnusson, 2002; Norwood, 2005; Price et al., 2011; Richards, 2016). I sit somewhere beyond a neutral or middle ground when delineating a spectrum of positions on permissive legislative AD practices, sitting (slightly) towards the supportive end. I am not alone in this, though; for example, Starks (who initially held a neutral personal stance but changed this following their AD research) (English et al., 2018) and Young (2020) conducted their research from a supportive ‘pro’ perspective. Meanwhile, Finlay and Hollins (Tuffrey-Wijne et al., 2018) conduct research alongside active political lobbying seeking to prevent permissive legislation in the UK. As baronesses in the House of Lords, they have an institutional power far beyond the role of a researcher. In the early stages of my research process I was worried about the issue of bias and specifically my previous involvement with Healthcare Professionals For Assisted Dying²⁵. I will use it here as a useful example to articulate my use of *critical*.

I am a middle-aged British, white, heterosexual, cis-gender, healthy, atheist male. As a specialty doctor in emergency medicine, I am a member of a profession with social status and secure employment. In short, I live a life of relative privilege and am not marginalized. While I have been exposed to much illness and suffering, it has always been secondhand (another person experiencing it). I do not have any first-hand experience living with an illness, being disabled, or of being a patient. In my professional role, I hold power and tacit knowledge within clinical encounters (Carel and Kidd, 2014), especially as a gatekeeper to an acute hospital admission. Critically speaking, I am carrying out research *about* a site of struggle and not *from* the site of struggle (Causevic et al., 2020). As such, I risk perpetuating practices or values that dominate or oppress others from an outsider's perspective (Braun and Clarke, 2013), which could take many forms: threatening participants' self-narratives, re-traumatizing them, or even providing a confirming influence on the WTHD (Van Wijngaarden, Leget and Goossensen, 2017).

In stating that I am carrying out research about a site of struggle I seek to highlight subtle differences in orientation between a constructionist interpretive paradigm with a critical paradigm. Thus far, a constructionist paradigm that recognizes the social location of knowers also seems congruent with my epistemological foundations. This would need prefacing of being congruent only in its ‘weaker’ form,

²⁵ I was (am still) in awe of the research from a neutral perspective (potentially as a slight hangover from my medical training). For an example of why and what this can achieve, see Magnusson's *Angels of death: exploring the euthanasia underground* (2002) (a book that is far too often missed/ignored within the WTHD literature).

as a 'strong' constructionist paradigm does not fit with my ontological foundation. Instead, a strong constructionist paradigm seems more consistent with a relativist ontology through constructing realities/holding that all knowledge is constructed through interactions (Braun and Clarke, 2022). A *weaker* form can accommodate the assumption that understandings can be constructed to reveal or reflect something about 'what is actually going on' (Braun & Clarke, 2022). The subtle difference I want to identify here between a weak constructionist and a critical approach is that a critical approach comprises an explicit interpretive orientation seeking to explore and explain in a manner that is also emancipative or transformative in some form (Ayton and Tsindos, 2023) consistent with the aims I have stated in section 1.1.

Returning to concerns surrounding my bias, I initially questioned myself and reflected on whether I was conducting activist research. However, Hale (2017) outlines crucial hallmarks that identify activist research that contrast with my aims, not least because I do not aim to support one political cause. This is not to say that my stance and who I am are absent from my research, just that I learned a researcher's situatedness could be something to capitalize upon and utilize rather than control or bracket out (Tufford and Newman, 2012). Interpretation can come from many contrasting reflexive positions that combine and clash to help illuminate and contribute further understanding. Crucially, my aims purposefully steer clear of normative claims surrounding the desirability (or not) of permissive legislative change; the site of struggle that I explore (and seek to contribute to understanding further and improving) is one wholly within the regulatory status quo. It is to the insider characteristics (specific attributes or experiences) that I share with potential participants (Braun and Clarke, 2013), such as being identifiable as supportive/pro and a medical professional, that I seek to utilize. As such, my insider characteristics influenced how and why I study this setting (section 1.2).

My professional role also caused me further concern regarding the potential for the disclosure of acts that break professional guidance or criminal law during data collection. Being a GMC registered doctor²⁶ comes with associated professional duties, as outlined by the GMC in its publication *Good Medical Practice* (GMC, 2013a). Of relevance, are the expected duties about acting on patient safety concerns, which state that doctors have a duty to "take prompt action if you think that patient safety, dignity or comfort is being compromised" (GMC, 2013a). I was unsure about my duties if practices that go against GMC guidance or even criminal law were disclosed to me during my study, related to those fears and uncertainties GPs have reported about providing medical documentation.

²⁶ Dual roles of clinician/researcher are common, with official training pathways and multiple opportunities for clinicians to enter postgraduate research.

Ethical tensions between having dual roles (of practitioner and researcher) have been well documented (Allmark et al., 2009) but tend to address the power dynamics between roles rather than the power dynamics of professional regulation impacting on the researcher's role. In researching oncology nurses' experiences receiving requests for AD, Volker (2001) (a nurse themselves) was likewise concerned about the disclosure of potentially illegal acts and their professional duty. To mitigate this risk, Volker conducted their research via direct mailing to a nursing organization's membership list, with participants writing back anonymously. Anonymity was used as a shield to protect the researcher from professional risk, and it is with this issue of research anonymity that I turn to next to discuss the research methods for my study which reveal a further influence on my theoretical background: pragmatism.

4.4 Anonymity

The theoretical and practical limitations surrounding confidentiality within academic research have been widely discussed across multiple methods and topics (Tolich, 2004; Israel, 2004; Scott, 2005; Clark, 2006; Wiles et al., 2008; Saunders, Kitzinger and Kitzinger, 2015a; Saunders, Kitzinger and Kitzinger, 2015b; Kaiser, 2019). I take confidentiality to refer to keeping divulged information secret (by not telling others), which stands in direct tension with the demand for research impact (not least via research outputs and dissemination). However, Saunders et al. (2015b) contend that many researchers conflate confidentiality with anonymity, which refers to the non-disclosure of research participants' identity (or identifiable details).

Anonymity is critical to academic research as the withholding of or masking identity can be crucial to participation (Gibson, Benson and Brand, 2012) and especially so with sensitive topics where participation could pose a threat to the participant (e.g., professionally, emotionally, legally) (Cowburn, 2005). Regarding questionnaires surrounding potentially contentious end-of-life practices, it has been shown that the more that identity can be withheld, the more likely participants may feel able to respond (Draper, Ives and Wilson, 2009; Merry et al., 2013).²⁷ In the early 1990s, the Dutch government addressed these issues by setting up a confidential commission researching Dutch AD practices. This exercise resulted in significant disclosures of ethically contentious practices, primarily

²⁷ On the other hand, some argue against research paternalism and highlight the power of recognition that comes from identification (Saunders et al., 2015b).

attributed to the legally protected anonymity guaranteed for respondents (Hendin, Rutenfrans and Zylicz, 1997).

UK researchers have no such privilege regarding their research or their research data. While the British Society of Criminology (2015) reports that researchers are under no additional legal obligation as citizens to report a crime unless it is related to an act of terrorism, financial fraud, or child abuse, researchers are liable to be summoned to appear in court if they have evidence relating to an identifiable criminal case (British Society of Criminology, 2015; British Sociological Association, 2017). Crucially, anonymity is only offered within the boundaries of the law (Palys and Lowman, 2010), and researchers have been compelled to hand over research information (Belfast Telegraph, 2010). Additionally, a researcher in Canada was subpoenaed to court to break anonymity, resulting from their research on AD (Israel, 2004). Researchers have even been jailed in the USA for refusing to break anonymity when a court order demanded they did so (Wiles et al., 2008). These issues gain relevance when considering numerous media reports in the UK of applicants and their families being referred to the police after their intention to go to Switzerland for an assisted death have become public.

Identity is something that can be revealed accidentally if participants were somehow identifiable due to the uniqueness of their experiences (Tolich, 2004; Wiles et al., 2008). This accidental breaching of anonymity is more likely in research involving small communities or rarer experiences (Scheper-Hughes, 2000; Saunders et al., 2015b).²⁸ Saunders et al. (2015a) found this particularly difficult when researching the small numbers of families who have experienced a relative in a vegetative or minimally conscious state, especially as some had already publicly stated (part of) their stories to the media. Given the ability to search on the internet for specific phrases or information, Tilley and Woodthorpe (2011) have even questioned whether we are witnessing the end of anonymity. These points seem salient considering my fears that I could have encountered reports of acts which breach professional guidance, or even criminal law, in data collection. However, anonymity is often applied ontologically towards anonymizing data rather than the participant (Vainio, 2012)²⁹, as the researcher often knows the identity of whom they are interviewing (Saunders et al., 2015b). This last point highlights an

²⁸ Scheper-Hughes's ethnographic research into a small rural Irish community offers a seminal example whereby village residents could recognize who was who within the research.

²⁹ Data is usually discussed as being in text format, but it can include multiple media formats (e.g., voice recordings, video).

inherent weakness in an ontological shift towards anonymizing data, as anonymity can be a crucial consideration long before turning on a digital recorder.

In seeking to learn from how others have provided anonymity in designing my study protocol, I found only limited information regarding the practical techniques used. Wiles et al (2008) report that researchers appear to pragmatically "workaround" problems involving anonymity to avoid legal and ethical pressures without explicitly saying how. So, taking inspiration from Volker (2001) and hearing about qualitative researchers on sex work pre-internet (who left business cards in phone booths), I devised my own pragmatic study protocol which prioritized the option of anonymity (as best as it could be achieved) from the very first point of contact in the recruitment phase. This anonymity protocol received ethical approval from the Faculty of Health Science Research Ethics Committee at the University of Bristol on 17/06/2017 (application reference: 52165). The way I designed this protocol meant that I would not need to know the identity of who I was recruiting for my study. It is to the methods of this novel anonymity protocol that I now turn to describe.

4.5 Methods

4.5.1 Recruitment

4.5.1.1 Design

Recruitment was facilitated by disseminating my recruitment call to the Swiss AD associations, UK-based AD lobbying organizations (both pro and opposed)³⁰, research leads at relevant representative/professional bodies³¹, and across social media. This recruitment call (Appendix Three) comprised a study summary and signposting to the study website. The study website was the primary portal for potential participants and can still be found at <https://assisteddyingresearch.wordpress.com>. Snowballing was utilized, where I encouraged those already interviewed to pass on my recruitment call to anyone they might know informally.

As a token of thanks, a £20 Marks and Spencer gift voucher was offered to those participating. The recruitment timeframe started a few months after receiving ethics approval, beginning in October 2017, and ran until May 2018.³²

Recruitment relied entirely on people contacting me via the university phone number given on the study website or via an anonymous private message facility on the study website. I utilized a phone call log sheet (Appendix Four) where I explained from the outset the need for the person phoning to use a pseudonym that they were comfortable with in case they had yet to read the study website. A discussion then took place regarding eligibility for the study and the likely time commitment.

I kept a log of all contacts received, summarizing why they were or were not eligible. I labelled individuals as belonging to one of the applicant-HCP-family/friend triad I described in chapter three

³⁰ Pro: Dignity in Dying, My Death My Decision, Healthcare Professionals for Assisted Dying, The Secular Medical Forum, the National Secular Society, The British Humanist Association and Exit International. Opposed: Living and Dying Well, Care Not Killing, Not Dead Yet, and the Christian Medical Fellowship.

³¹ Royal College of General Practitioners, British Medical Association, Royal College of Physicians, National Council for Palliative Care, Hospice UK, and the Royal College of Psychiatry.

³² At this point, I took an opportunity within my personal life to take a sabbatical from clinical and research roles to thru-hike Te Araroa (across the whole of New Zealand). Writing up my research was then subsequently affected by my return to an increased clinical role in response to the COVID-19 pandemic and then doctors' strikes, a role I continue in.

as constituting those involved in assistance talk. The identifier codes I utilized were **A** for an applicant, **HCP** for a healthcare professional, and **FF** for a friend/family member, followed by a number. These identifier codes were continued through transcription. The one piece of identifiable information I did receive at this juncture (if consent was given) was their phone number, which was linked to their identifier code. I kept these codes in a locked drawer at my university desk and then shredded them immediately after the interview in a university-provided shredder for confidential waste.³³ Those who wanted to keep this information private were advised to phone me back during office hours after thinking about participation and possible dates/times/locations for interview that they would be comfortable with and suitable for them. In this manner, participants could withhold their identity from the beginning of participation.

4.5.1.2 Eligibility

Eligibility was restricted to adults with experience of seeking or providing the medical documentation intended for use in an application for an assisted death abroad. The key criterion was that we would be talking retrospectively about experiences that had already happened (to mitigate the effect of the study on the WTHD), regardless of the outcome. I excluded those thinking about, but yet to act on, seeking access to medical documentation. Experiences involving the disclosure of the WTHD to an HCP when **not** seeking access to documentation as part of an application for an AD abroad were also excluded, in recognition of the importance of the fears surrounding the regulatory background and the key power differential inherent to encounters where documentation is also requested.

4.5.1.3 Sampling

A convenience sample was anticipated due to studying an uncommon and specific phenomenon in which the prospective pool of eligible patients was likely relatively small and hard to reach. I collected demographic data surrounding the details of the person who sought to apply for an assisted death and not the participant's demographic information. These details were collected for indicative purposes but also because they may have been needed if purposive sampling or a comparative

³³ This highlights a practical instance whereby 'complete' anonymity was not achieved.

analysis of people's experiences based on demographics were warranted. The demographic information I collected was as follows:

- Refused/gained documentation
- Age Group (18-40, 41-49, 50-59, 60-69, 70-79, 80-89, 90-99, 100+)
- Gender
- Regional geographic location (North, North East, North West, London, South East, South West, Wales, etc.)
- Faith
- Disabled
- Underlying clinical condition (category: neurological, malignancy, respiratory, genetic etc.)

Collecting the demographic information of the requestor seeking documentation for an AD application was primarily aimed at contributing to protecting the anonymity of the participants themselves. Additionally, I sought to create the potential to contrast experiences between different demographic characteristics during analysis, considering the practices of inclusion and exclusion relevant to assistance talk discussed in section 3.4. However, these aims were misjudged as the demographic details needed to be uncoupled from participant identifier codes to maintain the level of anonymity offered by my protocol. If linked to interview transcripts, they could have provided significant identifiers of the participant and/or requestors.

4.5.2 Data collection

Data were collected using semi-structured interviews, a method selected for two main reasons. Firstly, semi-structured interviews enable the exploration of personal experiences (Bryman, 2016; Bearman, 2019) beyond the mere reporting or recollection of events. Bearman (2019, p.3) quotes Schultze and Avital (2011, p.3) to highlight this:

"[T]hick description presents human behavior in a way that takes not only the physical and social context into account but also the actors intentionality. In this way, the meaning and significance...are made accessible to the reader".

Following from the literature on the wish to hasten death (WTHD), the topics discussed were likely to be sensitive, personal, and emotive. With some crossover from my clinical role, I felt the ability to begin with informal open questions at the beginning of a discussion could help facilitate a rapport and help put the participant at ease. In this sense, semi-structured interviews were a pragmatic method following on from the anonymity protocol and the research question.

Meaning and significance were also central to flexibility, the other reason semi-structured interviews were utilized (Bryman, 2016). Open questions that do not rigidly stick to a formulaic structure can help redress the power imbalance between researcher and participant, compared to the more hierarchical nature of structured interviews. In this manner, participants can lead the discussion and even construct the meaning of the questions themselves. Meanwhile, researchers can pivot away from a passive role to respond, reciprocate, and even interrogate, consistent with my theoretical foundations where the researcher's role can be seen to be a strength.

Preceding recruitment, I carried out two pilot interviews³⁴, which helped me evaluate and refine the topic guides used in interviews (Appendix Five) and gain practice in qualitative interviewing³⁵. Face-to-face interviews were conducted at a place chosen by the participant; for the majority, this was their own home. This meant I needed to know an address, which was treated as securely as phone numbers. Receipts for expenses such as train tickets showing identifiable information such as destinations were blacked out for anonymization purposes, and the originals were shredded.

For those who preferred a neutral venue, I booked venues such as commercial or university meeting rooms after being instructed of a suitable area. This protocol resulted in meeting some participants in

³⁴ One was with a person who had publicly campaigned for permissive AD legislative change due to their WTHD, and the other with a doctor who was known to me personally and therefore ineligible. These were not transcribed and not included in the study. They remain confidential.

³⁵ A notable conclusion from these pilot interviews was that the encouragement of using unidentifiable features in their recollections was time-consuming and distracted from the flow of the conversation. Subsequently, I decided that anonymization of this data would be better suited during transcription.

their homes and neutral venues with no idea of their identity (to this day) or having ever received any identifiable information (such as phone number). Telephone interviews and video call interviews were also offered. These were either carried out in a secure and private room at the University of Bristol or, in one instance, in my own home. For these interviews, the £20 gift voucher was posted with an address supplied by the participant in the phone call, which was only written on the envelope and posted immediately (with either no name or the pseudonym they gave).

The interviews were recorded using an encrypted digital recorder. The digital recorder was kept in a secure locked drawer while awaiting transcription. However, this happened as promptly as possible after the interview (usually the next day and then deleted following checks for trustworthiness). Likewise, electronic transcripts were kept on a secure, password-protected university server. Geographical information, names, or other specific identifiers were either redacted (identified as such within the transcript) or reverted to a generic description that they represented (e.g., GP practice, local hospital, specialist, Swiss AD association).

Consent was obtained verbally at the beginning of the interview and forms part of the individual transcripts, although it contains no identifiable markers as to the person's identity. Consent was able to be withdrawn but required the participant to contact me. A date of 1st December 2019 was given for withdrawing consent; this was given during the consent-taking process and stated on the participant information page of the study website.

To assess accuracy of the data, transcriptions were checked by one of my supervisors (JI), who selected four recordings and their related transcriptions at random. These transcripts have been retained with the consent given at the time of the interview for secondary analysis, including by researchers other than myself. Participants were encouraged to contact me with any questions or concerns following our interview, although none did that. Complaints were and remain possible by emailing the research governance department at the University of Bristol³⁶.

³⁶ This department acts as an independent body unconnected to research projects which investigates and resolves participant complaints. Their email address is research-governance@bristol.ac.uk (also given on the study website).

4.5.3 Safety protocol

My physical safety was a concern, considering I was traveling to meet people in their homes without knowing who they were. To mitigate the risk as much as possible, I devised and enacted a lone-worker plan with a trusted friend. I gave them the key to my locked drawer (containing the address of my destination) and the expected times of arrival/leaving the interview and arrival back home. I texted them on safe arrival at the interview with a pre-worded message, on leaving safely and on return. We had a mutually agreed emergency code word for a phone call or text, that would result in the break of confidentiality (by opening my drawer and calling the emergency services). This policy was the same if I missed my check-in texts by two hours.

I also had to consider possible scenarios regarding my professional duties, something also considered by those researching suicide as a tension exists between a duty of care to protect life and a participant's right to confidentiality (Gibson, Benson and Brand, 2012). Specifically, if a participant had disclosed a plan to kill themselves immediately following the interview, I would have been duty-bound to consider breaking confidentiality by contacting the emergency services. Participants were actively encouraged to plan regarding the possible emotional burden of the interview, such as choosing an appropriate time for the interview and having someone present following the interview for emotional support. Sources of support were also signposted on the study website.

4.6 Data Analysis

I used Braun and Clarke's (2022) six-stage method for describing and interpreting patterns across qualitative datasets to develop analytic themes. This updated their previous (2006) method, highlighting that themes are not something that emerge from the data (as things to be discovered) but are instead created by the researcher through a creative and interpretive *process*. These six stages are:

- 1) Familiarization
- 2) Data coding
- 3) Generating initial themes
- 4) Reviewing and developing themes
- 5) Refining, defining and naming
- 6) Writing report

I familiarized myself with the data by interviewing and transcribing almost all the data myself, with only four transcriptions transcribed via a third-party professional (adhering to the University of Bristol data protection policy). I began by writing a synopsis introducing each participant's transcript and the key points, including non-verbal clues not captured in the transcripts (e.g., where I felt that the participant was more emotional or stressing a point that was important to them). I also noted my first impressions, whether participants disclosed the reason for seeking documentation, and whether they received documentation and, if so, what type.

I then coded the transcripts electronically using NVivo coding software, starting after the first few interviews. I coded liberally to begin with, including coding some passages multiple times on different levels, at both a semantic level and on a more latent/interpretative level. However, my coding predominantly orientated more naturally towards the more inductive/semantic to keep the codes grounded in the participant's voice. Hundreds of codes were initially created after completing all the transcripts, which I condensed down to around 50 that were succinct and pithy enough, while still identifying the inherent meaning of the code. As a method contributing towards trustworthiness of my analysis, I discussed my coding of transcripts more in-depth with one of my supervisors (AM), who challenged my coding and interpretations from different theoretical perspectives.

I tried multiple methods to generate initial themes, including cutting all the codes onto strips of paper and spending many days re-arranging them to see which codes clustered together to tell a coherent story (figure five below). I discussed multiple iterations of these with research supervisors. Crucially, these discussions involved practices that Nowell et al. (2017) have identified as means towards establishing trustworthiness within thematic analysis, such as triangulating insights and theories within our group and checking the referential adequacy between themes and the source data.

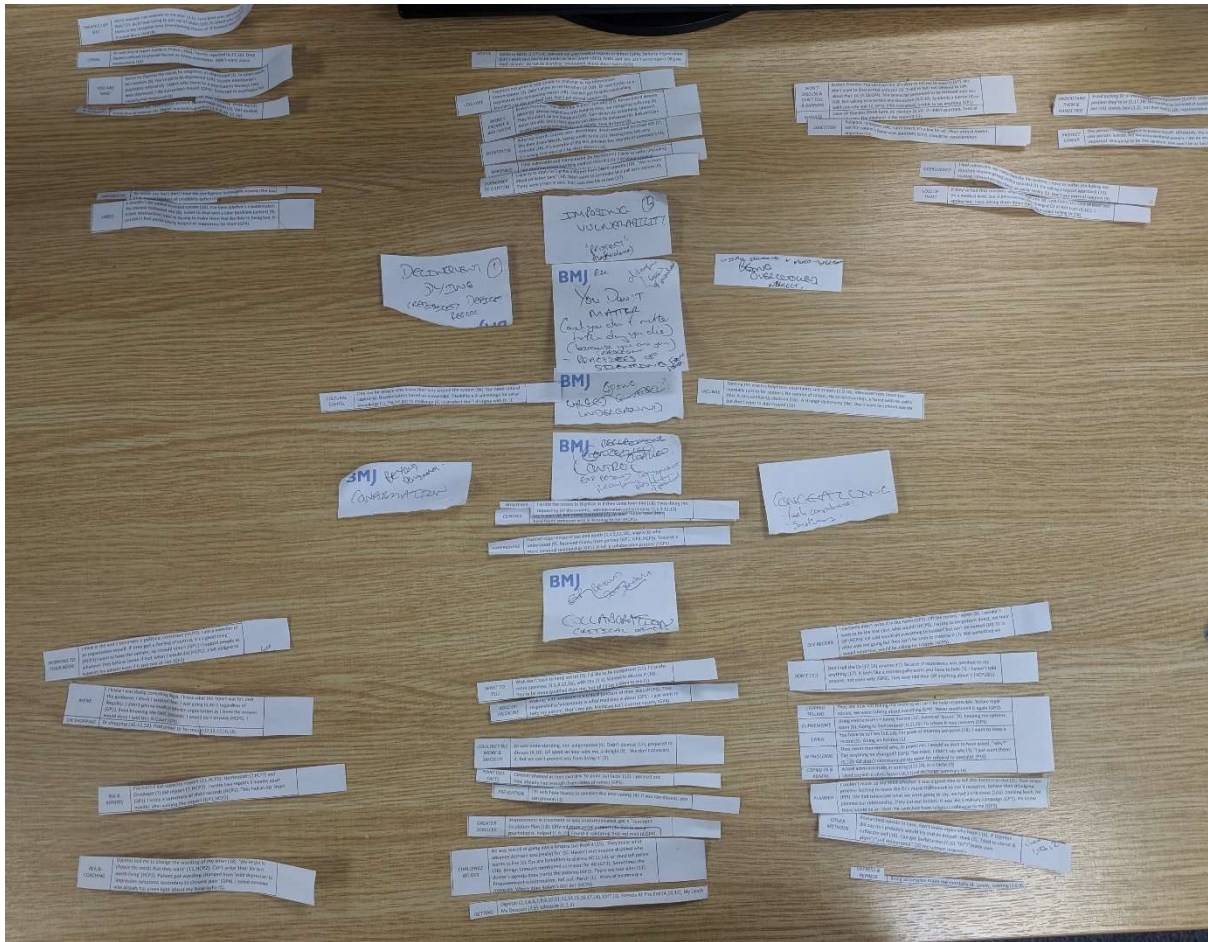


Figure 5. Stage three of data analysis

I also tried modeling themes using computer software (including experimenting with different shapes). However, I spent too long on the design and not enough time generating themes³⁷. I preferred tables, including when moving on to a more latent level of analysis. I have an electronic folder called ‘stage 3’ with all my tabulations containing snippets of thoughts about potential themes/sub-themes. To develop these outlines of what were largely sub-themes further, I sketched out potential theme ideas more fully by considering contradiction and how themes related or clashed with each other. I became stuck in a phase where multiple options existed for setting out the potential themes into a coherent narrative. It was like a storyboarding exercise for a film script and I sought to identify a beginning, middle, and end to presenting the themes. I found that stages five and six blurred together and were much less distinct than laid out by Braun and Clarke (2022). The crucial breakthrough in naming and refining themes happened after taking a step back from the process, instead writing about

³⁷ What I felt I needed in the 2020's was an app where I could move codes around with a swipe of a finger or delete with one touch, rather than drawing connected circles with lines.

the setting of the scene for the analysis which helped clarify the intertwining threads (sub-themes) of connection that identified a hierarchy or coalescence that spoke to coherent themes.

Reflecting on the time I spent toiling and froiling in stages five and six of the analysis shows the richness of the data I was working with. While I did not purposively sample in recruitment, the concept of information power (Malterud, Siersma and Guassora, 2016) helps to explain why. Malterud, Siersma and Guassora (2016, p. 1753) state that “information power indicates that the more information a sample holds, relevant for the actual study, the lower amount of participants is needed”. What is seen to be ‘relevant’ is impacted by the study aim, the sample specificity, the use (or not) of established theory, the quality of the dialogue, and whether cross-case analysis was utilized. As such, I benefited from a narrow aim, specific eligibility criteria and robust dialogue aided by my familiarity with the theoretical framing of AD as a discursive process and experience of discussing sensitive topics in my clinical role.

4.7 Summary

In this chapter, I have discussed the methodological choices I made to answer the research question. I began with the theoretical background to choosing a critical reflexive thematic analysis, linking this to the previous chapter and a theoretical consistency with framing AD as a discursive process. I reflected on my concerns about doing research about a site of struggle, not from a site of struggle and bias within interpretative analysis. I highlighted the importance of my professional background as causing concern if I encountered reports of acts which contravene professional guidelines or criminal law.

I discussed how anonymity in research is often applied ontologically towards data and how anonymity has been previously utilized as a shield to help mitigate professional risk. Subsequently, I presented a novel study protocol which prioritized a participant’s anonymity pragmatically, offering anonymity from the moment of recruitment, resulting in me not even knowing the identity of who I would be interviewing. It is to the results of what I have described here that I turn to in the next chapter, by answering my research question.

5 Findings

5.1 Introduction

In this chapter, I present the main findings of my study, a critical thematic analysis of 24 people's experiences of seeking or being requested to provide medical documentation for use within an assisted dying (AD) application. I begin by describing the outcomes of the recruitment process and the early stages of analysis that highlighted a significant dilemma faced by requestors: whether or not to disclose why they were seeking documentation. This dilemma informs the two themes I subsequently develop in turn. These two themes are:

- *The dangerous ground* captures a pervasive sense of risk and precariousness accompanying the disclosure of a wish to hasten death (WTHD) while seeking medical documentation
- *Sneaking off to Switzerland* captures the furtive nature of seeking an assisted death and the transformative descriptions of receiving a provisional green light

5.2 Recruitment

I received a total of 95 contacts from my recruitment call, almost all via telephone. However, not all of these were from people enquiring about participation, as they also included messages of support (from someone who felt the topic needed researching) and disagreement (from people who disagreed with the focus of my topic). From the first few contacts, I soon realized that I had not been prepared for the spectrum of knowledge family or friends had about the experiences of their loved one's attempts at gaining the medical documentation they required. This lack of preparation resulted in the need for more contextual probing during the initial contact than was required for applicants or healthcare professionals (HCPs) and a judgment as to whether they knew enough detail about attempts to get documentation. Despite having vivid recollections of their loved ones' WTHD and subsequent assisted deaths in Switzerland, 12 family members or friends interested in participating did not know enough about the medical documentation aspect and were ineligible.³⁸ The largest

³⁸ One participant (subsequently included as a family member/friend) mentions experiences of helping two friends seek medical documentation (two discrete episodes) but only had sufficient memory about the most recent of them. It is this most recent experience that is the focus of their participation.

ineligible group (14 in total) had hypothetical wishes about applying for an assisted death in the future but had not started seeking documentation.³⁹ Ten people were ineligible because their experiences concerned self-deliverance and seeking other methods for ending their own lives without the need for assistance or involvement of HCPs. Other ineligible experiences included recollections of the arrests of family members or being defrauded out of large amounts of money trying to purchase (illegally) the barbiturates used in AD. Figure six (below) summarizes participant recruitment:

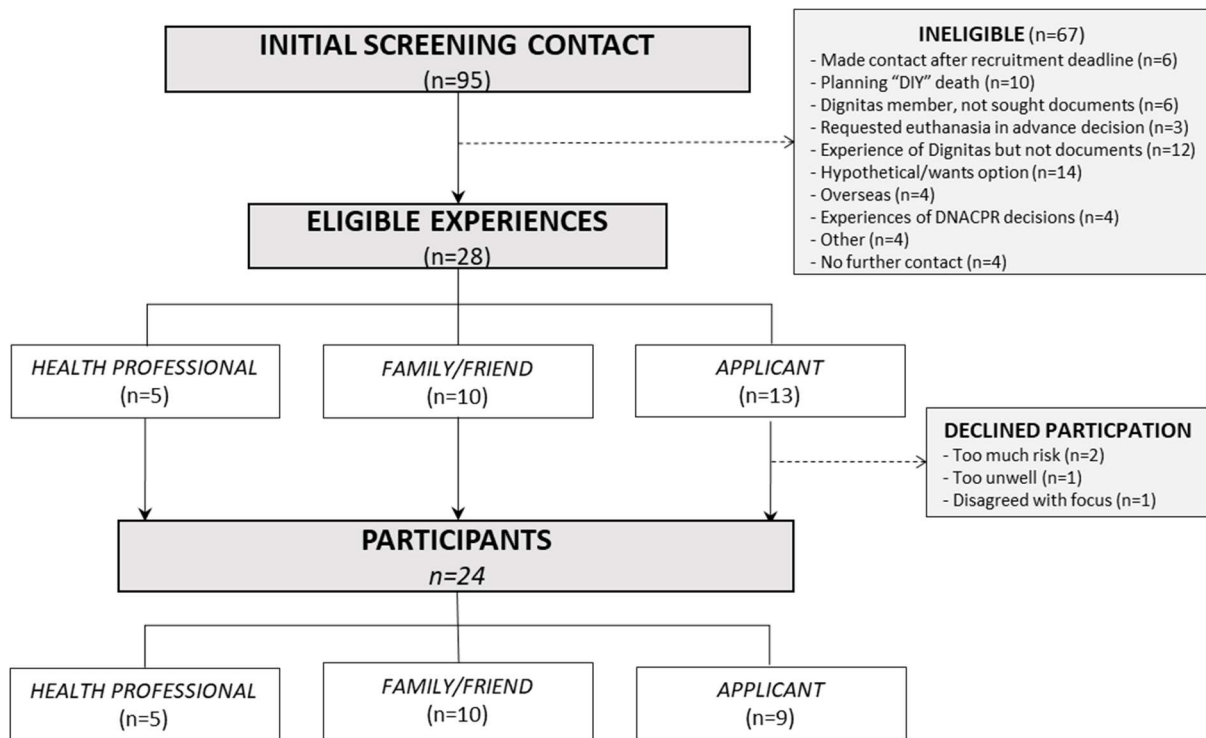


Figure 6. Participant recruitment

At the time of my recruitment call, I had defined the jurisdiction of my study as the criminal jurisdiction of England and Wales. However, I received interest in participation from people in Scotland and from within a jurisdiction abroad where AD is already legal. Crucially, the HCPs who had been asked to provide documentation were all registered with and regulated by the General Medical Council (GMC), leading me to reassess the complexity of the jurisdiction of interest and of the important of

³⁹ One participant (subsequently included in the study due to their experiences as a family member) had hypothetical discussions with an HCP about seeking their own documentation. However, as these were hypothetical, they are not included as a separate experience, but are retained within the interview transcript.

professional regulation. Subsequently, I changed the jurisdiction to one of professional regulation covering UK HCP regulatory bodies rather than criminal law (section 2.5).

In total, of the 95 contacts received, 28 people were eligible. Four people (all applicants who were applying for AD themselves) subsequently declined participation, with two stating that (despite my anonymity protocol) participation still carried “too much risk”. My prior assumptions regarding the need for, and such a focus on, anonymity within the study design were vindicated as many participants only agreed to participate due to my protocol and me not even knowing who they were. One participant felt too unwell to participate,⁴⁰ and one person did not want to participate due to their disagreement with the focus of my study (which they thought should have been on human rights). This resulted in a convenience sample of 24 people participating in total, which included:

- Nine applicants themselves (referred to by the letter **A** when quoting)
- Ten friends or family members who either supported the acquiring of documentation for an applicant or even did the acquiring of medical documentation on behalf of an applicant (referred to by the letters **FF** when quoting)
- Five healthcare professionals who received a request for documentation (referred to by the letters **HCP** when quoting)

It is important to note that while 24 people participated, only 23 interviews took place regarding 23 people’s attempts at seeking the option of an assisted death abroad. One interview consisted of a married couple (A9 and FF10) discussing their attempts at seeking medical documentation for only one of them.⁴¹ I only collected demographic data regarding the person who had sought the option of

⁴⁰ I had worried about this before setting up my study. However, as Wilkie (2001) contends, palliative patients “may very much wish to participate in a project even though their participation may cause them inconvenience, even discomfort, and may be time-consuming. Patients may wish to help and ‘give’ ”. My recruitment of applicants seeking AD for themselves is a testament to this statement.

⁴¹ In two other interviews, the participant’s spouse also entered the room and joined the discussion towards the end. Their contributions to the discussion are kept within the interview transcripts but did not form part of the analysis, largely because they did not contribute to the focus of the research question (unlike A9/FF10).

AD and who were the subject of the 23 discrete applications being discussed. I did not record the details of the participants and so to delineate this group from the group of participants, I will henceforth refer to these 23 people as the *requestors*. The importance of this point is that not all the requestors told their own story as some of them had already died; their stories were told by others (FF/HCP participants). Nine of the participants were requestors (the applicant participants), so their demographic information is reported as part of the whole (figure seven). These applicants were able to report their own characteristics. In contrast, the family/friends and HCP participants judged how their loved one or patient may have identified (which sometimes extended to them not knowing or being unwilling to define).

<u>GENDER</u>	<u>AGE</u>	<u>REGION</u>	<u>UNDERLYING CONDITION</u>	<u>DISABILITY</u>	<u>FAITH</u>
Male = 11	40-49 = 1	Scotland = 2	Neurological = 8	Yes = 14	Christian = 7
Female = 12	50-59 = 9	North = 3	Cancer = 7	No = 3	Athiest = 5
	60-69 = 5	Central = 6	Chronic Pain = 3	Unknown = 6	Humanist = 3
	70-79 = 3	South West = 7	Mental Health = 1		Unknown = 8
	80-89 = 3	South East = 1	Respiratory = 1		
	Unknown = 2	London = 2	Alzheimers = 1		
		East = 1	Unknown = 2		
		Overseas = 1			

Figure 7. Demographic characteristics of those requestors seeking AD (n=23)

17 interviews were conducted in person, three via video call, and three over the phone. Ten regarded contemporaneous applications (at the time of the interview), and 13 were based on retrospective recollection of applications where the applicant had already died. Whilst I did not collect the dates of the events discussed within these recollections, the majority seemed to have occurred within the preceding 12 months prior to interview. However, a few seemingly took place up to two years previous and one interview seemed to be discussing events from longer ago than this. Of the five HCP participants who had received requests for medical documentation, three were general practitioners (GPs), one was a consultant psychiatrist, and one was an osteopath.

5.3 Theme development

The reasons motivating peoples' desires for the option of an assisted death covered the broad spectrum of physical, psychological, social, and existential aspects of suffering seen within the WTHD

literature that I discussed in chapter three. These reasons (Appendix Six) highlight the relevance to my study and transferability of the international research on the WTHD and those who participated.⁴²

I was initially struck by the effort and prolonged commitment needed to gain documentation, including the requirement for repeated requests and dilemmas about whether to disclose the reasons for seeking documentation. To aid understanding of these efforts, I mapped out the journeys of how each of the 23 discrete requestors navigated the dilemma of disclosure and the subsequent outcomes in a) accessing documentation and b) their application status at the time of the interview:

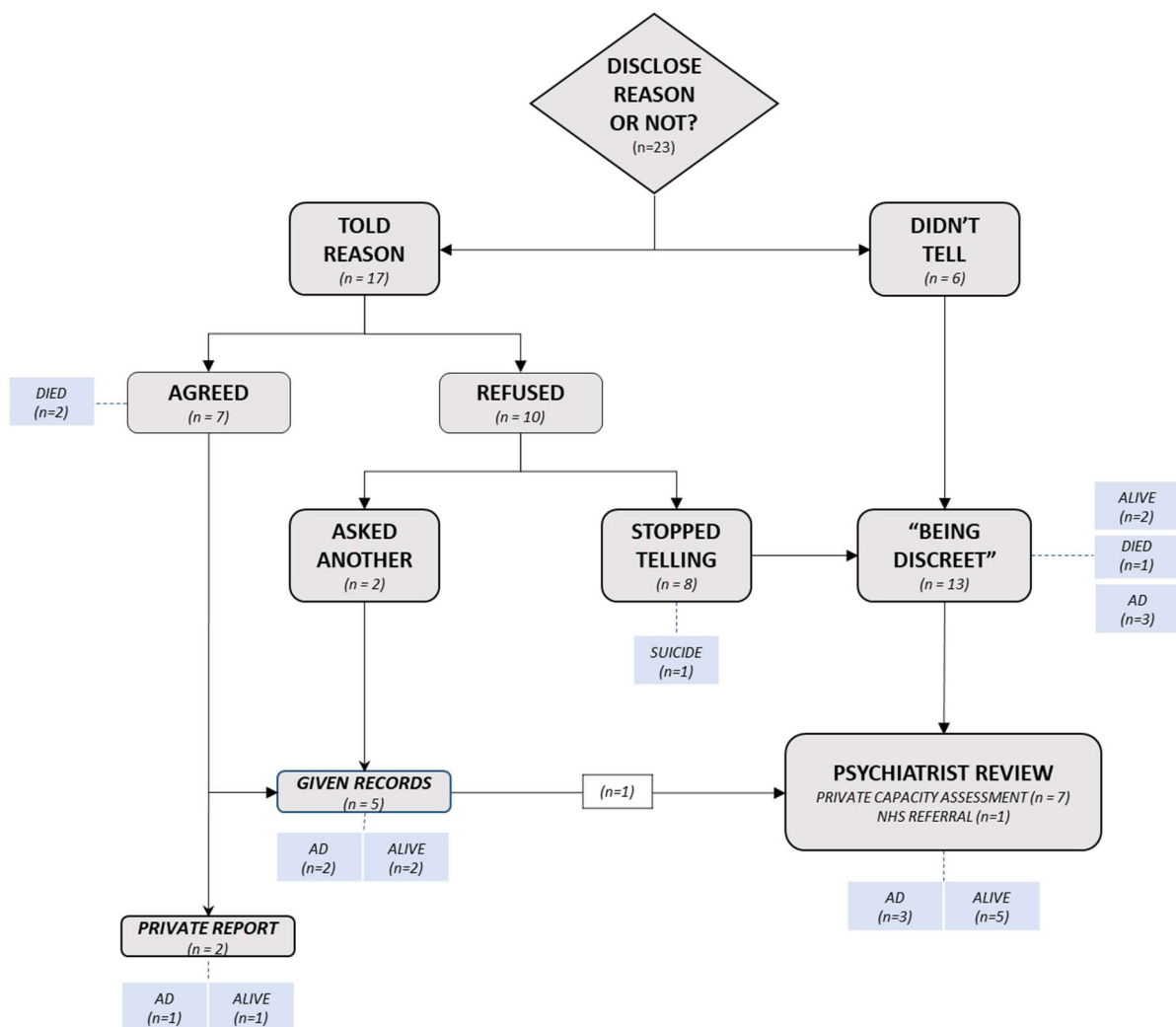


Figure 8. Navigating disclosure and accessing documentation

⁴² These reasons are also an example of a different level of analytic coding, representing thematic nodes within the coding stage (a collection of statements about a topic without further analysis).

Of the 23 requestors, nine had already received assisted deaths (five via Dignitas, three via Lifecircle, with one unknown), four had already received a provisional green light from a Swiss AD association (two from Dignitas, two from Lifecircle), four were still in the application process (three to Dignitas, one to Lifecircle), two needed further documentation to be able to apply, three had subsequently died from their underlying condition (after seeking documentation) and one had ended their own life (after being refused documentation).

Of the 23, 17 initially chose to disclose the reason for seeking medical documentation. Of these 17, ten had approached their GP (three of whom agreed to give copies of medical records, seven refused access), five approached hospital-based specialist consultants (two agreed, three refused), one approached an osteopath (who wrote a report), and one approached a homeopath (who wrote a report). Getting the appropriate documentation proved difficult for many, as not all medical records contained enough detail, resulting in the need to seek additional medical reports, written intentionally for use in their application. Specifically, eight sought an additional psychiatric report attesting to their mental capacity (as requested by the Swiss AD organization).

The journeys illustrated in figure eight show how the participant's experiences were broadly consistent with the descriptions of assistance talk as a discursive process. Using the seeking of medical documentation as a surrogate setting for assistance talk was vindicated as most participants disclosed their WTHD and reasons on multiple occasions over a prolonged period of time to multiple HCPs. Even the experiences of those who initially decided not to disclose why they sought documentation are relevant to understanding AD as a discursive process, as most were forced to discuss their WTHD eventually, whether they liked it or not (with a psychiatrist).

What I want to highlight within figure eight (above) are the pivotal experiences of the ten encounters that involved an initial refusal to provide documentation as they had profound effects. From the ten who had initially decided to disclose yet were refused, only two subsequently decided to re-disclose their reasons to another HCP. Many participated in my study out of anger at, or a sense of injustice from, their experiences within these encounters. Similarly, the fear that these refusal encounters could happen provided the rationale for why the remaining seven did not initially disclose their WTHD and reasons for seeking documentation. A concern for unknown others who may have to face the dilemma of disclosing a WTHD when seeking documentation, and a desire to improve the situation for them, motivated almost everyone's participation. These emotions were evident from the very beginning of my interviews and are present throughout the two themes I subsequently developed. I provide a coding structure underpinning theme and sub-theme development (Appendix Seven).

5.4 Theme 1: *The dangerous ground*

5.4.1 Theme introduction

The dangerous ground captures the pervasive sense of risk and precariousness accompanying the disclosure of a WTHD while seeking medical documentation. It captures something unique to the phenomenon for the participants compared to their other experiences of interactions with HCPs. To illuminate this theme, I articulate three sub-themes that combine to detail how disclosure of a WTHD was experienced as potentially unsafe. The first sub-theme, *losing control*, centres on the experiences of the power inequalities between the requestor and HCP. The second sub-theme, *mad or bad*, identifies a degrading heuristic described by requestors following disclosure of their reasons for seeking documentation. The final sub-theme, *feeling exposed*, then describes the perception of a pervasive regulatory threat that not only affects acts of assistance but acts of disclosure (as if discussing AD is itself prohibited), and ultimately the requestor's ability to access documentation.

5.4.2 Sub-theme 1: *Losing control*

This first sub-theme centres on the experiences of the power inequalities between the requestor and HCP, describing the encountering of the illusion of control inherent to seeking assistance from another (section 3.4). Although requestors may set out (in part) to seek a greater sense of control over their life (and death) by seeking the option of AD, the requestor was not the one who had control because they needed approval:

A5 *Even though they [Dignitas] have all the referrals, they get their team together and have to decide for themselves that you are suitable. Even if everyone says, 'take them', the bottom line is that they can still say no (219-222)...I didn't know when I first went down the Dignitas route that you submit everything, pay your money and then they decide if they are going to have you or not...that six weeks was like shit (335-348)*

FF8 *You're totally at the mercy of some [Swiss AD] organization about which you don't really know anything (295-296)*

In the first instance, I take describing being "at the mercy" of others (in FF8's quote above) to refer to the explicit power that the Swiss AD associations have over approval or refusal, something that is inherent to seeking assistance from another. The use of the terminology a provisional 'green light' (used by Dignitas) itself reflects this power involving a permission granted to proceed and controlled by an authority. However, this power is also applicable to the accessing and provision of medical documentation to be able to apply for an assisted death. To recap, 10 of the 17 who initially disclosed the reason for seeking medical documentation were refused. Three of them had asked the HCP to write a report, so being refused accords with GMC and BMA advice. Two of these three were then subsequently denied copies of their medical records following disclosure, as were another three applicants who had originally asked for copies of their medical records. Experiences of being refused documentation were described in devastating terms:

FF1 *I may well have walked into her [FF1's mother, the requestor] bedroom and punched her in the gut. That [being formally refused access to her medical records] was a significant blow to her, from an emotional point of view it literally destroyed her. For weeks after that letter...she was inconsolable (412-416)*

A6 *I left there [a clinic appointment with a UK consultant that involved a refusal to even discuss AD] thinking, 'oh my god, where do I turn now?'. I was feeling, I was feeling pretty rough...I just felt (sighs), God- shall I just slash my wrists and be done with it? I don't know, I was just very, very, very down (327-332)*

FF9 *He [FF9's husband, the requestor] was absolutely distraught, frantic, so stressed out [after being refused access to his medical records]. I've never seen him like that before and it was awful. Really awful. Yeah, there were tears, there was shouting...it was desperation (114-117)...So that was it, he gave up. He gave up the thought that he was going to go to Dignitas, and then things started getting really bad (139-141)*

Refusal was so devastating specifically because of the detrimental impact a lack of documentation had on the ability to apply for the option of AD. For A9, this was even so despite having been given copies of their medical records at the first time of asking as they were subsequently refused onward referral to a psychiatrist. A9 needed this report to attest to their mental capacity, as the Swiss AD association had questioned why they were on citalopram, an anti-depressant medication. A9 felt unable to

circumnavigate their GP's refusal to refer them to a psychiatrist despite multiple attempts at seeking a private consultation. By the time of being interviewed, A9 had abandoned attempting to progress with their application. Some participants related the explicit power to refuse requests for documentation (and thus not be able to apply for the option of AD) to the relational power HCPs held hold within the HCP/patient relationship and the ability to dictate the course of the requestor's care:

- A7** *The whole relationship with people changes when you become seriously ill...it's not the losing control of dying, that is going to happen, that is life. It's the losing control to others, who then have more of a say than I will (663-666)*
- FF3** *He [FF3's friend, the requestor] was in other people's [HCPs] hands and that was distressing...He was sailing a ship and he wasn't in charge of it, everyone else was in charge of it, if you see what I mean (650-658)*
- FF1** *It was very frustrating for her [FF1's mother] because she could not do anything herself to action this [apply for AD without copies of her medical records] other than to keep repeating what she wanted to do, 'I want to do this [AD], but I can't do it. Why can I not do it? Why are these people [the HCPs who refused her access to her medical records] preventing me from doing this?' (196-199)*
- A4** *I feel I am being manipulated. I feel I am being controlled [by HCPs] and there is a bit of me thinking, "why the fuck can't you just let me die". Why do I have to go through all this pain, all this rubbish and all this begging (852-854)*

What I feel the participants are describing is the encountering of the illusion of control postulated by Young et al. (2021) (section 3.4). To recall, the illusion of control postulates that in requesting assistance from HCPs to seek greater control over their own life and death, requestors **reinforce** existing social power relations, with the HCP having the power. A5 seems to sum up the perception of HCPs as gatekeepers that already possess an authority or power to approve or deny the application for an assisted death when they recalled telling their palliative care nurse about receiving a provisional green light:

A5 They [the palliative care nurse] were slightly shocked. [They said,] “**Who gave you the consent to do that [apply for an assisted death]?**” (my emphasis) (264-265)

Crucially, when reflecting on the power HCPs possess participants used language coated with risk, as something potentially unsafe/threatening:

FF3 Normally, when you put yourself in the hands of a care system, the care system engages you in a process in which you feel like you are in the centre. You are in a bit of a cocoon of safety. When you are doing this [applying for AD]...there is no cocoon of safety (306-312)...There is no support at all from the people you would automatically turn to in life for support, so you are alienated from that. It’s an alienating process (620-622)

A1 The fear wasn’t of [the doctor’s] power, I respect the power the Dr has got because they’ve earned it. It was the fear of the misuse of that power (432-433)

A2 I don’t know whether I could say [disclose they were seeking an assisted death] to them [their psychiatrist]. I feel that I would be on very dangerous ground for doing so (642-644)

A2 was unique within the study sample as the only participant seeking the option of an assisted death due to the suffering they experienced based solely on the grounds of their mental (ill) health. The quote of the *dangerous ground* that I utilize to frame this first theme was given in the context of their previous experiences as a voluntary inpatient on a mental health ward. Specifically, A2 was alluding to their fears of the power of psychiatrists to detain people under the *Mental Health Act 1983*, something they had not experienced personally but had met others who had, and specifically, A2’s perception that this power had been abused or misused by psychiatrists. While this was not something reported to have occurred by any of the participants in my study, being detained under the *Mental Health Act 1983* due to desires of seeking the option of an assisted death were reported to have happened by two people who were interested in participating in my study but were ineligible as they had not sought medical documentation. The fears of the use of the *Mental Health Act 1983* are salient because they serve as an example of how being on *dangerous ground* was felt to go beyond the power of approval or refusal. To illuminate the fears of HCPs power beyond approval/refusal that highlight the reinforcing of power relations I shall utilize two examples, starting with FF8:

FF8 *In the last couple of weeks before my spouse went off [to Switzerland to receive an assisted death] the doctor [their GP] said something like, 'I won't come around and see you unless you're going to go and see the professor' [a specialist in FF8's spouse's illness] (215-217)*

While this referral could be seen as an attempt by the GP to help the requestor by seeking to make sure FF8's spouse received the best medical care possible, FF8's spouse took this as a form of coerced care because of the perceived threat of withdrawing home visits, required due to the mobility needs of the requestor. The point I want to highlight is that the GP made this threat after finding out about FF8's spouse's AD application informally, deemed by FF8 to be an accidental disclosure from someone they knew socially who also happened to work with the GP. The reason why medical documentation had been sought was never disclosed to the GP by the requestor or their family. This example points to the tacit power enabled by the social position of the GP which meant that they were able to find out something about their patient that had gone undisclosed. What marks this experience as relevant to *the dangerous ground* is that the GP was also then able to use this information to coerce the requestor, because of the precarious position the patient was in.

A similar example was given by FF4, who had accompanied their parent to their parent's GP but was refused documentation by the GP after disclosing the reason why they were seeking it. FF4 described the GP subsequently actively obstructing their request to see another doctor within the practice, with FF4 recalling the GP saying they would block such a request using their power as the senior partner in the practice. This power held by GP partners was also something referred to by HCP3, who recalled the GP partners at their workplace refusing permission for HCP3 to provide copies of medical records to their patient. In both these scenarios, the faith of the GP partners was stated to be the reason for their refusals. This was stated to HCP3 by the GP partners themselves but was only presumed by FF4, based on previous experiences with a refusal of abortion from the same GP due to their faith. FF4 subsequently complained to the local medical director responsible for the area regarding the care they received:

FF4 *When we asked if we [FF4 and their parent] could see another [GP] partner they said no. After that, I contacted the medical director at the local health board [REDACTED DUE TO IDENTITY],*

and their suggestion was that we change GP. It took us probably four months to get into another practice and get my parent assessed [by a new GP] (106-110)

I take this quote as instructive of the social power reinforcement at the heart of *losing control* as the medical director's response did not identify that it was the GP that needed to change how they practiced, but the patient had to register with another practice. There was a significant material impact on the ability of the requestor to access and receive care because of this, as it took four months to register with and see a new GP. In both examples I have utilized (FF8 and FF4), it was the HCP who was in the socially dominant position and able to dictate the care received by the requestor, who was reliant upon the HCP for their care. Crucially, it was the disclosure of the WTHD when seeking medical documentation that created this reinforcement and the explicit exercise of social power.

Ultimately, what was feared about the outcome from a refusal (of documentation but could be seen to also apply to Swiss AD associations) was the possibility of the types of deaths that requestors had feared and set out to avoid in the very first place by seeking the option of AD. For example, FF4's parent subsequently ended their own life after being refused documentation, with their death being described by FF4 in highly traumatic and gruesome terms involving a protracted death over many weeks. FF2 reported that their spouse was resuscitated after suffering a respiratory arrest (when breathing stops) following the administration of morphine despite a DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) decision being in place. Crucially, this had happened while the care team knew that FF2's spouse had already applied for an assisted death in Switzerland. As a result of this episode, FF2 recalled that their spouses' palliative care team subsequently avoided increasing doses of opiate analgesics during the remainder of their care despite suffering increasing pain for which morphine helped, something also reported by FF9:

FF9 *I'd be saying [to the palliative care nurses] can I give him [FF9's husband] some more morphine because he's screaming, he's in agony (172-173). Towards the end it was almost every day that I was ringing up, [asking] 'what can I do?' And quite often they would actually say, 'no, you can't give them anymore' (182-184)...It just wasn't what he wanted (216)*

This experience sums up the risks of being *on dangerous ground* by *losing control* as ultimately "it just wasn't he wanted" and illustrates the contradictory nature of seeking greater control yet reinforcing a social reliance on HCPs. The risks of reinforcing this reliance include not only the refusal of

documentation and, thus, the inability to continue with an AD application but also risks experiencing the very deaths requestors had originally sought to avoid.

5.4.3 Sub-theme 2: *Mad or Bad*

This second sub-theme describes a degrading heuristic regarding the requestor's credibility following disclosure of the desire to seek the option of an assisted death. To begin with, five participants reported a referral to either a psychiatrist or a psychologist as the immediate reaction from an HCP following disclosure of the reason as to why they were seeking medical documentation. While these were individual reactions, this sub-theme is also represented by the requirement for eight psychiatric assessments reported by participants (figure 8). The heuristic described is of 'a WTHD = mental health concerns':

A3 *I tried to speak to a doctor about this whole process...and they said, "I'd like you to go and speak to the psychiatrist" (156-158)...My understanding is that the GP had to be careful, and they thought, "right, if there's assisted suicide being mentioned...it's a psychiatric referral" (216-218)*

A1 *[The neurologist] never mentioned depression until I said that [disclosed that they would seek the option of an assisted death]...they were visually kind of shocked by it. That's when they [the neurologist] said, "I'm diagnosing you as depressed" (170-177)*

In this last quote, A1 reports being diagnosed as depressed in reaction to disclosure by a specialist they had only just met for the first time in an outpatient clinic. A1 had been asked about how they felt about their diagnosis and had replied by stating how it had clarified their desires to seek the option of AD. Crucially, A1 had professional experience of working within mental health and found this heuristic as deeply unprofessional, involving no further discussion or assessment. In the first instance, I take it that the specialist labelling A1 heuristically as being depressed was experienced by A1 as a strategy to shut down and limit the conversation. It was this experience that I think provided the basis for A1's perception and fears about the potential "**misuse of...power**" (quote seen earlier on p.76) by HCPs. Additionally, A1 also related this episode to two experiences they had when they were younger and at their workplace which both involved credibility deficits (one recalled in the quote below):

A1 *I was in my 30's, before I went back to university, I had tattoos on my lower arm...I was teaching this group and on the last day it was boiling hot, so I put a T-shirt on and a very light jacket. And then come lunchtime I just didn't think, I took the jacket off and as soon as they saw the tattoos, and I know it isn't the same now, but the relationship totally changed with them, they didn't see me as a peer any longer (625-633)*

I take this reflection to connote that A1 viewed the heuristic of 'mental health concerns' as containing a negative judgment, where - as with tattoos in their workplace - they were no longer seen as "a peer" in the discussion with their HCP after disclosing their desires to seek the option of an assisted death. A2, who was the only participant seeking the option of AD for underlying mental health conditions reflected on something similar when they likened this heuristic to the sociological concept of stigma:

A2 *When you mention Dignitas, it feels like you're almost using the word as a swear word but far, far worse, it's just got such a stigma attached to it (803-805)*

Link & Phelan (2001) highlight that the sociological concept of stigma can be, and has been, defined in a variety of ways but tends to describe attributes or characteristics that act to discredit/devalue the bearer in some way by being viewed as tainted or contrary to social norms. This concept is relevant to AD as a discursive practice within Winington's (2016) suggestion that seeking AD can be positioned as deviant when viewed through an authoritative palliative lens, which positions AD as oppositional to a palliative care ethos. A2's reflection seems particularly insightful when viewing quotes from other participants using this lens of social stigma. Many participants frequently sought to separate, rationalize, and position a WTHD as distinct from mental illness. Specifically, participants seemed to be describing themselves, their loved ones, or their patients as **not mad**:

A3 *It's [desiring the option of AD] quite a different thing from a general psychiatric problem (570-571)*

FF4 *They [FF4's parent] weren't depressed in any shape or form, they weren't that sort of person (114-115)*

FF2 *They [FF2's spouse] may have been frail, but their mind was as sharp as a razor (308-309)*

A7 *I'm taking a logical...and pragmatic approach to it (410-411)*

FF8 *I don't think it should be called assisted suicide, I think it should be called assisted dying because the whole process is very different and it's much slower and you're more aware of what's going to happen and I think it's probably less traumatic than a suicide. A suicide is a kind of sudden thing and leaves people, you know. There's lots of feelings of guilt **and all the rest of it** (my emphasis) (529-533)*

In the last quote above, I took "all the rest of it" to refer to the social stigma surrounding suicide, which FF8 is resisting. Not being *mad* was more than just a statement regarding the perceived rationality and well-considered nature of a WTHD but a resistance to the labeling and stigma associated with mental ill-health, which they had now encountered for themselves via the negative heuristic of 'a WTHD = mental health concerns' (most for the very first time, unlike A2). Interestingly, I captured this resistance to labeling in an exchange between the married couple. This exchange is instructive of the mad in *mad or bad* as it provides an example of the sub-theme happening and the only time in my research that I could analyze an interaction (as opposed to recollections):

FF10 *The thing is, if you are in that situation [experiencing their spouse's chronic illness] you are bound to be depressed. It's a depressing-*

A9 *Yeah, but I'm not, I don't feel depressed.*

FF10 *Yeah, but you are (218-221)...*

A9 *...I'm not depressed. I'm past all that. It doesn't do any good...*

FF10 *...I'm sorry, it's got to be depressing, it's got to be.*

A9 *No, it's just life. I just see it as [normal] life (232-234)*

What I want to highlight from this exchange is how the FF10 repeatedly refuses to believe A9 when they state they are not depressed because they **must** be and, by extension, anyone else must be if they are in the same position. A9 also went on to report their perception that their GP seemed to describe conceptualizing mental capacity differently depending on the decision A9 was making. After disclosure of seeking an assisted death, the GP created a treatment escalation plan involving A9 documenting their refusal for attempts at resuscitation if their heart was to stop, which A9 was deemed to have the capacity to make. However, A9 also recalled the GP then refusing onward referral to a psychiatrist (alongside the unsolicited sharing of their opposition to AD), being told that mental capacity for an assisted death needed to be judged over an extended period. Regardless of the reasons for this refusal, what I want to highlight about this recollection is how doubts were introduced regarding the requestor's credibility specifically because of their decision to seek the documentation required for an assisted death application. A2 also recalled being undermined by a psychiatrist after disclosing that they were seeking to apply for an assisted death, based entirely on the suffering they experienced from their underlying mental health conditions. A2 recalled their psychiatrist saying that suffering based entirely on mental health conditions would not be eligible for an assisted death anywhere, something A2 knew to be factually incorrect after researching this, contacting a Swiss association and being told that it was possible (and was in the process of applying for).

The perception that AD applicants **must** be mad or less credible and reliable also helps explain the potential space where other negative pre-judgments could be employed heuristically within HCPs' responses to a WTHD, such as those articulated by Tuffery-Wijne et al. (2018) regarding AD being granted for those with intellectual disabilities, as they **must** be suffering or living pitiable lives.

Being *mad* (or resisting the label) was one of the first things I was aware of when analyzing the first interviews alongside recruitment. By the time of my ninth interview, I was able to ask questions to participants about this perception helping develop my analysis further by identifying another related component of the heuristic (*mad or bad*). The following quote illustrates an example of co-construction:

I One of the things which seems to be coming out [from my analysis] is that if someone mentions 'I'm thinking of going to Dignitas', there's a reaction that somehow you are mad

FF3 *Or bad!*

I Yeah, mad or bad? (403-407)

In total, six participants recalled HCPs responding to a request for documentation by immediately explaining why they (the HCP) thought AD was morally wrong. The reasons reported included: a lack of evidence of the need for AD, the role of health professionals as never to end life actively, the concern about coercion of family members seeking inheritance (in general and not explicitly applied to the applicant), and that palliative care was sufficient in ameliorating a WTHD. Two examples include:

- A6** *The oncologist drew back in their chair- and they had got a fountain pen in their hand, and they threw the fountain pen on the desk...and then leant back in the chair and screamed at me, "I am here to make you BETTER, NOT TO KILL YOU!" They then slammed my file shut, shoved it on a pile of files, turned to the nurse and said "EXAMINE HER!"...Anyway, she examined me, I got dressed and she opened the door and I was shown out (250-258)*
- A7** *They [the specialist] said, "it's really not right, the people over there [in Switzerland] shouldn't be allowed to kill you" (184-185)*

Receiving these moral objections begins to frame the bad in *mad or bad*, especially considering that the HCP's personal moral opinion was not something that had been requested but imposed. Crucially, this moral objection was not only linked to individual reactions but implied as something more ubiquitous throughout the medical profession (that the medical profession was officially opposed to AD as a whole):

- A2** *To just be able to talk openly to somebody is actually really therapeutic...Particularly to a doctor rather than just someone I've grabbed off the street- I've found it makes a huge difference, it really has, [I] feel a burden lifting...*
- I** *...Is there something about me being a doctor then? I mean I am one...and you know I am, but if I wasn't...there's something about my background...what's that?*
- A2** *I think it's just because everyone else in the medical profession has been completely one hundred, more than a hundred percent, against it (814-830)*

A7 *I'm aware, all these [healthcare] professionals have certain...pressures and their own professional restrictions of their profession's stance against being involved (250-252)*

FF1 *They [the HCPs who refused access to FF1's mother's medical records] took the stance, their profession's stance by the way, which is, 'we will not be a party to this activity' (788-789)*

FF10 *They [their GP] said they wouldn't talk about it [assisted dying]. They just said, 'we cannot be perceived to be involved with this'. They said, 'you've got every right to have your medical records but as far as anything else is concerned I can't take any sides in this'. They said, 'we're more about palliative care' (**sighs**) (my emphasis) (34-37)*

In this last quote, I understand what the GP was trying to articulate: one of palliative care's guiding ideologies is seeking to neither hasten nor prolong death (World Health Organization, 2023). In this framing, palliative care is positioned in the middle of a spectrum. However, I take FF10's exasperated sigh at the end of the quote as the signifier of their contrasting opinion that they felt palliative care was a specialty that did take sides. In fact, criticism aimed at palliative care's organizational stance was an ever-present throughout many of the participant's experiences, such as this example:

FF9 *The other thing that peeves me off a little bit are the palliative care doctors. They kind of make me feel like I haven't got the intelligence to navigate my way around things and that's not very nice...(492-494)...*

I *...I can't remember what you said before we turned the recorder on, I don't know, the sense was derogatory...*

FF9 *Arrogance-*

I *Yeah, that was it.*

FF9 *Just an arrogance that they are the ones with the all-seeing eye, they know best, yet they know nothing about these people [who are] dying [the requestors] (505-510)*

The importance of this last quote, however, does not lie in the criticism of individual or organizational oppositional stances but about the way this is communicated which sums up how *mad or bad* is

experienced. *Mad or bad* captures how the situationally dominant HCPs are perceived as (deeming themselves) capable of making complex moral decisions on behalf of patients yet pre-judging the requestors as somehow less capable of making these same decisions for themselves. It is this credibility deficit that contributes to *the dangerous ground* surrounding the disclosure of a WTHD and explains why participants resist this labeling.

Only one out of the 17 requestors who initially disclosed their reasons for seeking medical documentation (FF7) described uniformly positive experiences of interacting with HCPs throughout their illness. FF7 felt supported throughout their spouse's illness, specifically describing the disclosure encounter as non-judgmental. Other descriptions of encounters which felt safe to disclose a WTHD included not being dismissed (A7), not being made to feel that they were doing something wrong (A4) and of HCPs being impartial (A2). I take these descriptions to point to why those participants who experienced psychotherapy as part of their care seemed to recall them as positive, helpful and therapeutic experiences as they were perceived as a neutral space to talk about their WTHD. A psychotherapeutic approach contrasted greatly with the experiences of a hostile and judgmental medical encounter.⁴⁴ As per Pestinger et al (2015), requestors sought to be listened to and responded to in a manner that recognized them as rational knowers, and not judged as being *mad or bad*. HCP5 (a practicing GMC psychiatrist who provided a medical report for a patient of theirs) reflected similarly when pointing out that conversations about people's desires to end their lives are a normal and commonplace part of the therapeutic relationship:

HCP5 *Having an open channel of communication is critical for being as helpful as you can be. I mean, we talk about suicide all the time with people. It's interesting that assisted dying is different. Obviously, there are legal differences but talking about wanting to be dead is absolutely a normal day's work (400-403)*

The point I want to re-iterate from HCP5's quote is that improving experiences of assistance talk, including those encounters whereby people disclose that they are applying for an assisted death,

⁴⁴ It is interesting to note there were no problems reported by participants in accessing their dental records, even when the reasons for disclosure were given.

requires no legislative change. A “normal day’s work” does not need to include a reinforcement of power relations that contributes to social stigma.

5.4.4 Sub-theme 3: *Feeling exposed*

In this third and final sub-theme, I capture the sense of precariousness surrounding disclosure further by describing how participants *felt exposed* to the regulatory frameworks that govern AD and the seeking/providing of medical documentation when applying for an AD abroad. To begin, fears of criminal law and the *Suicide Act 1961* were widespread. For example:

FF1 *It was a very cautious time [applying for the option of AD in Switzerland]. All of a sudden, we [FF1, their mother as the requestor, and other family members] were very much aware of what we were doing could be otherwise perceived as being 100% illegal (756-758)*

FF4 *The first thing they [the GP] told me was they would report me to the police (86-87)*

These fears were not unfounded, as four participants reported experiencing police involvement when applying for the option of AD in Switzerland. These included A7’s spouse and FF8’s family members, who were questioned by the police before they traveled to Switzerland for assisted deaths after anonymous tip-offs to the police. In a similarity to Swiss AD procedures (section 2.3), FF8 recalled the discussion being video recorded (which they felt was for documenting proof of mental capacity and the lack of coercion). The police also investigated FF2, but in their case, after returning from their spouse’s (assisted) death in Switzerland.

In the last of the quotes above, FF4 describes receiving a threat of being reported to the police from their parent's GP. Notably, this threat seems to have been given with a clear understanding of the *Suicide Act 1961* as it was purposefully aimed at FF4 as the assistor and not their parent as the requestor. While none of those who reported police involvement (or threats of involvement) were charged, some of the family/friend participants reflected on their roles by using criminal terminology about themselves:

- FF3** *The person who is dying [the requestor] is unable to make these arrangements themselves because they are dying. The idea that my friend could sort out, or that anybody in that terminal state...is laughable. Of course there are accomplices. Every single person...they [the requestors] couldn't make those arrangements and do all this themselves (330-338)*
- FF10** *I've [A9's spouse] done the whole correspondence and the communication with the doctors and the things like that...my spouse can't write. I'm an accomplice for sure, there is no question (661-667)*
- HCP1** *I knew I was doing something illegal, but I just dismissed it. I knew I'd do it [write a medical report for their patient's application for AD in Switzerland] (340-341)*

Regulatory fears were reported to have a deterrent effect in some scenarios. For example, when A8 asked their MND support group for information on who to contact about applying for an assisted death, they refused to help. Similarly, two separate banks refused to transfer A7's funds for their application to the Swiss AD association. A9 went as far as to ask friends with access to Class-A drugs to source a supply of illegal drugs (to overdose to death), yet they, too, refused due to the fear of a police investigation.

Having established the presence of regulatory fears, what interests me is how they acted to deter not only acts of assistance but also communicative acts of disclosure and discussion. FF2 ceased plans to set up a support group specifically for those bereaved by an assisted death after receiving legal advice that public discussion of AD could be seen as providing encouragement or advice to others. Similarly, many recalled being told that **discussing** AD was itself prohibited:

- HCP4** *It's easy in the UK. You just go, "no, [I'm] not allowed to talk about it" (AD) (312)*
- A3** *They [the specialist] said, "I'll stop you there, we're not allowed to discuss this with our patients" (157-158)*
- FF10** *They [A9's GP] said they wouldn't talk about it. They just said, "we cannot be perceived to be involved with this" [AD] (34-35)*
- A8** *The minute I mentioned it [Dignitas] they [a psychologist] said, "I'm not allowed to talk about that" [AD] (247-248)*

On the surface, these recollections suggest that the GMC guidance is not well known or not clear enough to all doctors and other HCPs. However, I take them to also demonstrate a tacit power held by HCPs to gatekeep what is and what is not discussed within the clinical encounter. These instances seem to be examples of practices of exclusion when viewing assistance talk as a discursive practice and are contra to GMC advice which states doctors should “be prepared to listen and to discuss the reasons for the patient’s request” (GMC, 2022). Interestingly, FF8 described a related experience within (healthcare) academia:

FF8 *I told you the thing about my son? He wanted six months off his course because he wanted to just be home and spend some time with his mum. He was doing [REDACTED] at [REDACTED] and he told his tutor [why]. He ended up having a meeting with the head of the faculty and a solicitor or lawyer or something from the university and they said to him, “we can give you compassionate leave because your mum has got a lot worse and you want to spend some time with her but that’s what you need to say. **You can’t say** (my emphasis) my mum’s decided she’s going to Switzerland [for an assisted death] in three months’, four months’ time or something like that, you can’t say that because if you say that we may have to report it to the authorities, it might threaten your professional registration when and if you qualify’ (469-479)*

FF8’s recollection provides an example of how legal and professional fears combined to affect the perception of what could be said, or more accurately in FF8’s son’s case, what could be documented. Unlike the previous examples set within clinical encounters he could seemingly say/disclose the reasons to his supervisors, but that this could not be documented or recorded.

It is entirely possible that HCPs shut down conversations surrounding AD out of regulatory fears, but what characterizes *feeling exposed* further is the ability and power HCPs possess to mitigate these risks compared to, and to the detriment of, requestors. To begin to elucidate this, I will focus on the experiences of two of the three GPs in my study, starting with HCP3. HCP3’s patient had requested a medical report from them for use in an application for AD. HCP3 subsequently consulted with their medical defence organization and was advised to not only refuse the provision of a report but also refuse access to medical records. HCP3 did as instructed but remained worried about something they had said to the patient while doing so, that they thought the patient already had enough documentation to apply (via the copies of letters from specialists the patient had already been copied in on):

HCP3 *When I spoke to the MDU they said that their concern was fitness to practise from the GMC but also criminal aiding and abetting. They used the words 'aiding and abetting'. I think it would be really difficult, it's quite an extrapolation. The patient already had the information, it's not like I printed it out and gave it to them, they already had it. They already had the information in front of them...So, I don't think there would be a case for that.*

I *How did this feel?*

HCP3 *Did I feel exposed? Yes, I did feel exposed (221-229)*

HCP3 was so concerned regarding this singular action that I am the only one they have ever told. HCP4 reported feeling similar regarding a singular comment they made to a patient. HCP4's situation differed because they are a GMC-registered GP working abroad in a jurisdiction with permissive AD legislation. HCP4 was explicitly worried about a comparative remark they made to a patient who had already been refused an assisted death due to not meeting the criteria set by this jurisdiction. This one-off comment regarding the differences in the laws of their host jurisdiction and those of the UK was a significant concern for them:

HCP4 *I mentioned to them that patients have to go to Switzerland because you can't have it legally in the UK. Which they are now exploring [and applying to]. The legal advice I have got is that I shouldn't have told them that because I am now aiding them (50-53)*

The possible extra-territorial reach of the *Suicide Act 1961* and of being GMC registered created a concern for HCP4 as they feared a possible GMC fitness to practise investigation (+/- prosecution) on return to the UK. The precarious nature of being an immigrant was also at the forefront of their fears, as any regulatory proceedings against them could ultimately lead to losing their livelihood and ability to remain in the jurisdiction. Subsequently, HCP4 stopped receiving further AD training because of the risks involved. HCP4 also revealed a further insight to how *feeling exposed* contributes to the structural formations of *mad or bad* exists through the requirement for many of the requestors in my study to see a psychiatrist. In the quote below, HCP4 reveals that referring their patient to a psychiatrist (following disclosure of a WTHD) was as much about mitigating their professional risk, as it was about the patient's care:

HCP4 *I wouldn't have asked them [the requestor] to see a psychiatrist if they hadn't told me that they wanted assisted dying because I wouldn't have needed to prove there wasn't a mental health problem.*

I *It was about proof?*

HCP4 *Documented. About it being documented, written down. It was about having specialist documentation...to protect me (124-129)*

This stands in stark contrast to the experience of FF8's son within academia, where it was the documentation of the reason for a request (for compassionate leave) was the feared and avoided action. What I find most striking about the fears of HCP3 and HCP4 is just how exposed they felt from these singular comments, and how those fears were then magnified by the responses from their medical defence organizations. They were genuinely worried that their livelihoods could be at risk if anyone found out, with both only recalling these events due to the anonymity afforded by my research protocol. I think this level of fear is best understood as a reflection of the legal trap that Huxtable (2009) highlights that still remains within English and Welsh criminal law. To recall, the legal trap describes the possibility that someone could yet be prosecuted within England and Wales under the *Suicide Act 1961* (as no statutory guarantee exists for non-prosecution), despite most acts of assistance when seeking AD in Switzerland likely falling within the factors that tend against prosecution (Appendix Two). A8 succinctly summed up this pervasive fear:

A8 *Just because nobody's been prosecuted, that doesn't mean that someone can't be (229-231)*

Both HCP3 and HCP4 reasoned that it would have been highly improbable that their actions could have been construed as assistance (or contravened GMC guidelines). However, what dominated their concerns (and seemingly their defence organizations advice) was the **possibility** of regulatory/legal transgression, not the probability. It is *feeling exposed* to a possibility of legal/regulatory transgression that unites the fears of HCPs receiving requests with those requesting documentation.

Having described how the possibility of regulatory sanction contributed to HCP3 and HCP4 actions, I will discuss how these impacted on FF1 and FF4. In an attempt to protect their loved ones from *feeling exposed*, FF1's mother had disclosed that they were seeking an assisted death in Switzerland to everyone and anyone (including their GP and palliative care specialists). As part of their application

process, they had been receiving copies of all their medical records while investigations failed to reveal any pathological reason behind their symptoms. This continued to be the case until a scan (reported verbally to the family) did show pathology, which seemed to explain FF1's mother's symptoms. However, when the family requested this scan report, it was the one document they were refused access to. This document was the crucial piece of information that the Swiss AD association stated they required to be able to give a provisional green light (which the family was led to believe would be forthcoming). The family requested the scan report via a Subject Access Request to their GP and palliative care specialist, but both refused. The reasoning was provided by the palliative care specialist in a subsequent letter:

FF1 *"I [a palliative care specialist] must advise you [FF1's mother, the requestor] that I am unable to release your health care records or part of them to you. The advice that I have received i.e. me, under Section 2 of the Suicide Act 1961 would be encouraging or assisting your attempt to commit suicide. The director of public prosecution views this as a serious offence in law and it carries a penalty of imprisonment" (404-409)*

FF1's sibling phoned the Information Commissioners Office (ICO) helpline for advice on accessing this scan report, as they perceived it to be their right under the *Data Protection Act 1998*. However, they were told by the ICO that the doctor was correct to refuse their request, reportedly being told that the *Suicide Act 1961* trumped the *Data Protection Act 1998*⁴⁵. To this day, FF1's family is still unsure about their parent's underlying medical condition. I will return to discuss this point in the discussion chapter that follows this.

These events exemplify how the regulatory threat and the HCP's social power can combine to the detriment of the requestor. HCPs, positioned in the socially dominant position within this encounter, could mitigate the perception of the regulatory risk in *feeling exposed* by denying access to medical records. While the refusal seems to exemplify the explicit power held by the HCPs there seems to be an additional tacit component that relied on the HCP's knowledge of the importance of what this scan would mean for an AD application. As such, *feeling exposed* also describes a HCP's determination that the regulatory risk of criminal law or a GMC fitness to practise investigation outweighs the data rights of requestors and the risk of a requestor contesting the refusal of access to medical documentation.

⁴⁵ Another Swiss association subsequently accepted an application (and provided an assisted death) without this scan report.

Being unable to challenge a refusal for documentation was also something encountered by FF4, whose parent was refused access to medical records and then obstructed from seeing another GP. FF4 had attempted to challenge the GP's refusal but was also rebuffed by another doctor. Crucially, FF4 then helped their parent to register elsewhere but did so to mitigate drawing any further attention to their parent's attempts at applying for the option of AD rather than further contest the decisions they received. Both FF1's and FF4's experiences serve to highlight the contrast with HCP3s and HCP4s surrounding their ability to mitigate the different risks they faced within the regulatory framework. The HCPs had the power to mitigate the risk they faced whereas the requestors were unable to mitigate the risk to their data rights specifically because of the reason why they were seeking medical documentation, disclosing their WTHD. Linking to the first sub-theme of *losing control, feeling exposed* can also act to prevent the progression of AD applications through multiple further mechanisms inherent to regulatory fears such as not being able to talk about it and not feeling (or being) able to challenge HCPs. It is a precariousness from specific regulatory fears that is unique to the phenomenon of seeking an assisted death abroad, and seems to be summed succinctly by FF3:

FF3 *The difference with [applying to] Dignitas is that if something goes wrong, a tiny little thing goes wrong, you can't go (668-669)*

To summarize, it is to a regulatory threat of a possibility, and not probability, that pervades *feeling exposed*, not only deterring acts of assistance but also acts of disclosure and discussion. Crucially, *feeling exposed* also relates to the social power reinforcement seen in *losing control*. Socially dominant HCPs can mitigate the regulatory risks they face by seemingly determining the risks of criminal law and professional regulation outweigh data rights/the risks of requestors contesting their data rights/care. Meanwhile, requestors risk exposing their - already precarious - AD applications yet further if they contest refusals to provide documentation. Even if they do, requestors can still face barriers regarding access to documentation because of the reason why they seek the documentation in the first place.

5.4.5 Locating the researcher: *feeling exposed*

I designed my research protocol because I too *felt exposed*. Initially, when the recruitment protocol began to work, I felt vindicated that I had designed a protocol that meant participants felt safe enough to disclose these events. However, on reflection during analysis and the development of *the*

dangerous ground it became clear that I had also created it for my own ends, as it reassured **me** that I was safe to hear what they had to say.

Some participants stated they would have been more than happy (proud even) to have their names associated with the research, unafraid of legal consequences. Ultimately, though, I decided to retain control regarding anonymity because I had also created the protocol to protect myself and my career. I had created the very thing within my protocol that participants were then describing within their experiences of their dilemmas surrounding disclosure.

5.4.6 Theme summary

This first theme of being on *dangerous ground* captures the sense of risk and precariousness surrounding the disclosure of a WTHD when seeking medical documentation for use in an AD application. Disclosure risked what requestors had set out to mitigate by seeking an assisted death: *losing control*. Being refused documentation, including copies of their medical records, was devastating and could mean an inability to apply for an assisted death. In seeking a greater sense of control over their death requestors reinforced their reliance on HCPs, thereby relinquishing control, and risking the very deaths they had feared in the first place.

Sometimes, refusal to provide documentation (including copies of medical records) was driven by HCPs *feeling exposed* to a pervasive medicolegal threat. *Feeling exposed* not only functioned to affect acts of assistance but also of disclosure of a WTHD and avenues for assistance talk. Requestors also *felt exposed*, as a requestor's right to their own information was subordinate to the perceived risks faced by HCPs (defined by possibility, not a probability). To kick up a fuss and challenge HCPs meant further exposing themselves and their applications for an assisted death.

On other occasions, refusal was entwined with a HCP's moral objection to AD or perceived to be linked to institutional opposition. A degrading heuristic was encountered that associated a WTHD with mental ill health, which called into question the credibility of a requestor. Experiences of a *mad or bad* heuristic in response to the disclosure of a WTHD describe a credibility deficit, with HCPs deeming themselves capable of making complex moral decisions for and on behalf of their patients, whereas the requestor's capability was questioned.

Ultimately, *the dangerous ground* describes disclosure of a WTHD when seeking medical documentation intended for use in an AD application as potentially unsafe testimony. The risks,

injustices, and pre-judgments faced by requestors all follow uniquely from disclosure and within a context of seeking information and knowledge about themselves/their health status as entitled to under data protection law.

5.5 Theme 2: *Sneaking off to Switzerland*

5.5.1 Theme introduction

The second theme, *sneaking off to Switzerland*, captures the furtive nature of seeking an assisted death and why. The first sub-theme, *being discreet*, captures a panoply of practices employed by requestors (and those that helped them) aimed at circumnavigating *the dangerous ground*. The second sub-theme, *the green light*, encompasses the largely transformative descriptions of receiving a provisional green light from a Swiss AD association.

5.5.2 Sub-theme 1: *Being discreet*

At the very outset of seeking medical documentation requestors faced an initial dilemma about whether they could or should disclose their WTHD and reasons for seeking documentation (Figure 8, page 72). This dilemma describes an initial wariness of the HCP's likely response, as illustrated by the following quotes:

A4 *Because I have to have all this documentation and because it is so difficult in the UK because we know that not all doctors are in agreement, you have to tread so carefully [about disclosing the reasons for seeking documentation] (767-769)*

I *When you went to ask for [copies of] your [medical] records, did you have any concerns about being refused?*

A1 *Yeah, I did a risk assessment. I had to work out whether to take that chance or not (382-384)*

Describing the disclosure dilemma as encompassing the need to carry out risk assessments that weighed up the likely response of those disclosed to sums up a commonplace occurrence. These disclosure risk assessments were carried out almost every time a disclosure decision was faced. I first encountered risk assessments during the recruitment process for my study when two eligible applicants declined to be involved in the study because taking part already brought "too much risk" to their application process. Some participants recalled carrying out these risk assessments because they had already received a warning of the potential for encountering *the dangerous ground*. Specifically, the warnings received were to avoid disclosing their reasons:

FF9 *He spoke to them [Friends At The End] and they said, 'don't tell the doctor what it's for, just don't tell them what the letter's for' (324-325)*

A4 *Those who belong to Dignitas and Lifecircle...what we're advised is...don't tell them [doctors] that you are seeking an opinion for this reason (44-46)*

Not all participants received these warnings though, and even if they had, some still wanted to disclose their reasons based on previous experiences of their relationships with HCPs, wanting to be honest with them. Regardless of forewarning, subsequently encountering *the dangerous ground* was a seminal experience. Participants reflected on their experiences of *the dangerous ground* by echoing the very same warnings about disclosure that others had already been given:

I *...If anyone came to you seeking advice what would you tell them?*

FF9 *Don't tell the doctor what you want the letter for. Just find ways round it and just don't trust anybody (473-476)*

FF10 *Big mistake mentioning it to the doctor, big mistake (32)...*

...In hindsight, if I was to do it again for somebody, I would definitely tell them not to tell the doctor anything. And that's not nice (710-712)

FF1 *There is only one thing that I regret and have learnt out of this. This is the one thing that I try to put across to others. Don't tell anyone. Anyone that can have control over your ability to*

choose to use one of these services abroad. Don't tell them, keep it to yourself, keep it very, very close knit (935-938)

I take these quotes as reflecting a loss of trust in HCPs in their ability to hear or respond appropriately to their requests and WTHD after encountering *the dangerous ground*. Similarly to how participants generalized beyond individuals when they encountered moral disapproval (of AD) within the sub-theme *mad or bad* (section 5.4.3), they also generalized about their loss of trust in HCPs as a collective:

A6 *I was panicked because I thought, 'if they've [a specialist] had that reaction, I'm not going to get them from anyone else...what is my GP going to do?'* (282-284)

A7 *Here was this intelligent professional [a specialist] coming out with this. I went completely off them...when doctors are coming up with puerile things, it does make you lose your faith in them as a whole* (452-457)

FF3 *...Oh, he [FF3's friend] didn't really trust any of them [HCPs] after that (274)...There is no support at all from the people you would automatically turn to in life for support, so you are alienated from that. It's an alienating process* (620-622)

FF9 *Because of his [FF9's spouse] experience with his GP he was petrified of saying anything to anybody (124-125)...Anybody in the medical profession became the enemy and not to be told* (370-372)

It is requestors making risk assessments and deciding not to disclose their WTHD and the reasons why documentation was sought (regardless of whether advised by others due to their experiences or something learned themselves) that identifies the first furtive aspect of seeking an assisted death. Participants described the purposeful utilization of a panoply of practices to avoid disclosure to circumnavigate *the dangerous ground* and stay in control of their application process. Documentation already received as part of routine care was the easiest to use and did not require disclosure; examples included: outpatient clinic letters, imaging reports, and hospital discharge summaries.⁴⁶ Purposefully

⁴⁶ This concurs with the documentation most often seen in the study by Imhof et al. (2011), who analyzed the documentation received by a Swiss AD association (section 3.6).

avoiding the clinical encounter was also commonplace and easily achieved through utilizing the administrative system. Subject Access Requests were capitalized upon not just because of a requestor's data rights but because a reason was not required to be given.

Where interactions with another were unavoidable the use of euphemisms seemed widespread, something I reflected on with FF5 in the quote below:

I They [FF5's spouse] had already mentioned they were thinking of going to Switzerland?...That's one thing I'm finding: euphemisms...no-one seems to be saying 'I'm going to Dignitas for an assisted death'?

FF5 *Sure...we were being discreet about it (169-174)*

'Going to Switzerland' is a well-used euphemism for going abroad for an assisted death from the UK (Gauthier et al., 2015), and almost all participants in my study used it at some point. It actually means 'going to Switzerland for an assisted death' with the word Switzerland often being used as a replacement for the name of the Swiss assisted dying association applied to (e.g., "Switzerland requested it"). I noticed when transcribing the interviews, that I too had started using this language in the later interviews, highlighting how I was becoming more familiar with the colloquialisms and language of UK-based assistance talk. Other euphemisms I encountered included requestors having 'made other' or 'alternative plans' or 'arrangements' (for death/dying), or that palliative care 'wasn't for them'.

Lying was also a frequent and purposeful tactic for requestors when giving reasons for why documentation was needed couldn't be avoided, with some of the applicant participants reflecting on this as inherent to the process of the AD application:

A4 *It is me being manipulative as well [by lying] to try and get the report. Why do I have to go through this? (854-856)*

A2 *I feel as though I have to make something up and kind of go sneaking off (642-648)*

Examples of lying included giving reasons for needing medical records as being needed for power of attorney applications or holiday insurance. FF1 went as far as enlisting a family member who was a

practicing medical doctor to write a letter attempting to overturn a refusal for medical records. This family member wrote to their parent's GP requesting medical records, stating they had been requested to give a medical opinion.⁴⁷

The use of private medical consultations was not an uncommon tactic, being utilized within 14 out of the 23 discrete applications. In total, five requestors paid for a private medical consultation (at a cost in the region of £300 each) and lied during them about why they had sought a second opinion into their care (as they were only after the clinical summary produced from the consultation). However, for A4, lying backfired as they were subsequently refused an assisted death by a Swiss AD association specifically because of a lie they had given about the reason for seeing the private specialist. While the specialist's report not only detailed their medical problems (as intended by the applicant) the report also mentioned the possibility of surgery as a possibility for alleviating one of their symptoms. A4 did not want this operation, but the Swiss AD association refused their application as they had been offered a surgical option to help relieve their suffering. This example offers a contrasting risk to those previously seen within *the dangerous ground*, with the existence of risks to an AD application also inherent to not disclosing.

Practices of non-disclosure are critical to understanding *sneaking off* because requestors can still fulfil the administrative requirements of their Swiss AD applications without ever needing to disclose their WTHD here in the UK. In fact, out of the 23 discrete applications discussed in my study, two went on to receive assisted deaths in Switzerland without ever having mentioned, let alone discussed, their WTHD or their plans to a UK-based HCP once. One of these was FF5's spouse, and it is to one of FF5's experiences that introduces a further furtive component of the sub-theme *being discreet*. After FF5's spouse's (assisted) death in Switzerland, FF5 phoned their local coroner's office in the UK (while still Switzerland) to inform them of their intention to repatriate their spouse's body. Specifically, FF5 had questions about the administrative processes of doing such a thing:

FF5 *[The coroner said] "If you [FF5's spouse] want to avoid a criminal investigation, don't go down this route"...They [the coroner] made it clear that they were calling me in their own time [and not in an official capacity] (255-257)*

⁴⁷ A request using this lie was also refused (and would likely have regulatory repercussions for this doctor).

FF5 recalled being warned by the coroner that repatriating their spouse's body could result in a criminal investigation and advised FF5 to arrange a cremation in Switzerland instead, which they subsequently did. FF5 then drove the ashes back into the UK, avoiding the customs regulations on repatriating bodies and the need to register the death; they already had a death certificate from Switzerland.

FF5's experience highlights two further points about the furtive nature of applying for an assisted death. Firstly, the avoiding of attention can continue long after an assisted death (and this is why some only participated in my study only due to the offer of anonymity). Secondly, and what I will move on to develop to complete this sub-theme, is that *being discreet* also refers to how some of those who receive requests for documentation/assistance utilize their knowledge or social position (purposefully and discreetly) to help requestors circumnavigate *the dangerous ground* and avoid scrutiny.

Out of the 23 discrete applications in my sample, 11 involved receiving a purposefully written medical report for their application. Nine were mental capacity assessments surrounding the patient's choice, meaning the reason for seeking a report must have been disclosed. Of relevance, one Swiss AD association responded to my recruitment call with concerns that my research could adversely impact UK-based doctors that helped their members by writing medical reports because these doctors do so only on the basis that "nobody will know" (Personal communication, 2017). As such, I provide a redacted copy of one such medial report (Appendix Eight) to provide evidence that these reports are indeed being carried out by practicing GMC-registered consultant psychiatrists. HCP1 was one of these doctors and recalls *being discreet* when purposefully writing one such medical report for their patient in this quote:

HCP1 *The time I realized they were [asking for a medical report], they said to me, 'would you be willing to write a medical report?', and I jumped in [quickly] and said, 'do you mean, to whom it may concern'? (167-169)*

By purposefully masking the identity of the intended recipient, HCP1 felt they could mitigate *feeling exposed* to the regulatory background by offering plausible deniability about their intention. This careful use of language was also something reported by FF10 when they were writing A9's personal statement as part of A9's application for an assisted death:

I Did you know that you needed medical records to go to [the Swiss AD association]?

FF10 No. We didn't have a clue, we just wrote to [the Swiss AD association]. [The Swiss AD association] wrote back very quickly, I have to say they are right on the ball saying this is what we need. They got me to change my letter umpteen times because I was saying things that I shouldn't have been saying.

I Like what?

FF10 Anything about [A9] being depressed for one, had to come right out of it. Anything like that had to come out of the letter (209-216)

FF10 seems to me to be describing a Swiss AD association coaching what to write in an AD application, in this instance, one not written by the requestor but their spouse A9. While I took this coaching to have stemmed from the association itself *feeling exposed* to the Swiss regulatory background (in this case Swiss criminal law regarding mental capacity), the role taken by the Swiss AD association is subsequently revealed to be a rather blurry one. In between assessing a requestor's eligibility and advocating for someone to become eligible lies an important question about how depression is screened for during the application process. To recall, A9 had been unable to circumnavigate their GP's refusal to refer them onto a psychiatrist, subsequently ceasing efforts to continue with their AD application. However, A9 also recalled subsequently trying to end their own life twice with two different methods.

The important point I seek to raise from these examples is how they all mirror how the requestors responded to *the dangerous ground* by utilizing practices that in some form cloaked their advice or support from being noticeable to others. Along with the purposeful lying by requestors to gain access to medical documents they seem to provide examples that correlate with Magnusson's (2002) study in which he argued that a culture of deception about AD practices was all-pervasive in the jurisdictions he studied (where AD was illegal). As such, in the main *being discreet* captures the furtive nature of seeking the option of an assisted death in Switzerland by describing a panoply of practices utilized by requestors **and** HCPs. Requestors often purposefully utilized these practices to avoid *the dangerous ground* after losing trust in HCPs to hear their WTHD and requests, while professionals utilized them to avoid regulatory risk and exposure of their tacit support.

To return to the disclosure risk assessments introduced at the very beginning of this sub-theme, it was this possibility of support from HCPs, or at least lack of opposition, that formed an important consideration when weighing up whether to disclose their reasons for seeking documentation. HCP3

recalled that their patient had swapped into their care a couple of months before asking for medical documentation, switching away from one of the GP partners with a strong religious faith (who subsequently told HCP3 not to provide access to the patient's medical records). Both FF4 and FF7 reported researching GPs who had either previously gone public in their support for permissive AD legislation or had already been publicly involved with an assisted death. In essence, disclosure of a WTHD can be a strategic decision.

Crucially, when participants felt they could disclose their WTHD safely, these conversations became an opportunity to probe a WTHD to uncover together the understandings, meanings and intentions behind the request for an assisted death. For HCP3, their patient's disclosure of their WTHD and reasons for seeking documentation led to the uncovering of a false belief that their patient held. Part of the requestors reasoning was based on a diagnosis of benign tumours,⁴⁸ alongside a more clinically significant diagnosis. More strikingly, A4 canceled their (already scheduled) assisted death in Switzerland after discussing their WTHD with a stranger. A4 had utilized a thorough hospital discharge summary to fulfill the administrative requirements for medical documentation without the need or inclination to discuss their WTHD with their HCPs. However, a chance encounter with a stranger led to A4 having further social interactions within supportive networks of like-minded people seeking permissive legislative change. Eventually, A4 found new accommodation, which, combined with the newly formed social networks, ameliorated a large part of the social conditions that had motivated their request for AD. As such, *being discreet also* highlights the risks of repressing a WTHD (and the reasons behind it) as well the benefits of an open discussion.

⁴⁸ Benign tumours are those that are unlikely to spread or cause harm. However, they were understood as a cancer which was only likely to progress, contributing to a fear of the future.

5.5.3 Sub-theme 2: *The green light*

This final sub-theme pivots from the dilemma surrounding disclosure of a WTHD to illuminate the reasons why requestors were still willing to risk *the dangerous ground*, namely the receiving of a provisional green light from a Swiss AD association. As such, this final sub-theme brings my analysis full circle to describe what it is that was uniquely experienced by having the option of an assisted death.

To begin, receiving a provisional green light was described uniformly by participants in striking terms as something positive and often transformative. For example:

A1 *I got an email back from Lifecircle saying ‘everything’s fine, you’ve got the (provisional) green light, it’s not a problem’. So, I got the [provisional] green light. I’ve never been a religious person, but you know when you hear about people being reborn...all that evangelical thing? I was like WOW! I don’t drink, but I really felt I had (514-518)*

A direct correlation was reported by participants between the precise moment of receiving a provisional green light and striking improvements in well-being, all of which persisted to some degree. Every single applicant who had received a provisional green light reported their mood improving dramatically from that very moment onwards, as did the friends/family and HCP participants:

FF2 *The relief was palpable, so palpable. It really was their [FF2’s spouse] attitude, it completely changed. They were just happier (691-692)*

HCP3 *Interestingly, after they [HCP’s patient] had heard from Dignitas that it was going to be going ahead, their energy levels improved...They were able to do more, they were eating more again (366-370)*

FF1 *My mother she was visibly happy, the change in her mood from being in that dark place...Her mood changed she was again suddenly very buoyant. She was back to the person I remember before she had any issues...She was visibly happy, visibly buoyant. It changed her mood, all of a sudden, she had what she wanted which was her own decisions, her own control over her own life...my mother was overjoyed. Overjoyed. I’m not using words because they’re good words to use, I’m using them because that’s the actual response from her. She was overjoyed.*

And from every point from that point onwards was an upwards slope. Her mood, her peace of mind, her mental wellness, her mental state. Everything was on an upward trend from a very, very dark place (554-569)

FF8 *She [FF8's spouse] was much happier [after receiving a provisional green light]. It was quite weird actually, because it felt like she'd gone back to how I remembered her, to begin with. She was always very lively and that's how she came over for the last few weeks [of her life] (307-310)*

In FF8's quote (above) they seem to describe the opposite of the 'fractured personhood' that Chochinov (2023) describes accompanying a WTHD (section 3.2). Instead FF8 seems to be describing the provisional green light as restoring their spouse's personhood. Interestingly, requestors did not once report these possible effects within their original motivations or reasons for initially seeking an assisted death; they only seemed to discover them after receiving a provisional green light. However, something stated in the initial motivations for seeking an assisted death was actualized through receiving a provisional green light and was succinctly summed up by A5:

I *Does it still feel good?*

A5 *No. It doesn't feel anything. It's like I don't feel good that I've got home insurance, it just is. Do you feel good that you have home insurance? Do wake up every morning going, 'yeah, I've got home insurance!' Car insurance, it's the same. You don't do you? You just wake up, get in the car and go. Think about it.*

I *It's not having the worry about not having it? I might worry-*

A5 *If you didn't have it, exactly!*

I *It's an absence of worry?*

A5 *There you go, yeah (358-368)*

A1, A5, A6, and A7 all stated that the provisional green light enabled them to live life more fully and not dwell so much on their fears for the future. A provisional green light mitigated their fears of the

future/dying somewhat and meant that they were now (and what they had sought all along to be) in control:

A7 *It means you can get on with living...maybe I will make that decision, I might not. It's fantastic to be in control (340-342)*

Regardless of how much their need for personal care increased, how much pain they (still) experienced, or how much they (still) feared the future, from that moment on, they were all described as more manageable because they **chose** to experience them. In this manner, this small sample provides further empirical evidence for Gandsman's (2018) suggestion that the option to die can interpolate a choice to live (section 3.3). For some participants in my study, seeking and receiving a provisional green light was as much about providing a greater sense of being in control and choosing (how) to live as it was about choosing to die.

It is essential to state that I am not seeking to make causal claims about or overstate therapeutic outcomes based on a small self-selected sample. Instead, the point I seek to make is an observation how these findings are themselves possibly under-reported, under-researched, and under-theorized within the literature on the WTHD. In this sense, experiences of any possible therapeutic effect from gaining a provisional green light may have also *sneaked off to Switzerland* along with some of the requestors.

5.5.4 Theme summary

To conclude, *sneaking off to Switzerland* captures the furtive nature of seeking an assisted death and why. *Sneaking off* is characterized by a panoply of strategic practices that define *being discreet*, encompassing the avoidance of disclosure and the avoidance of attention to an application or the support given to an application by a professional including lying. For two out of the 23, this meant never disclosing their WTHD to any UK-based HCP. *Sneaking off* reflects the loss of trust in the ability of HCPs (as a collective) to hear and respond to a WTHD appropriately. *Being discreet* is aimed at circumnavigating *the dangerous ground* and retaining control (over the application process). As part of this, risk assessments are carried out to gauge the likely reactions of others following the disclosure of a WTHD. Safe encounters for disclosure include those that lack the characteristics of *the dangerous*

ground or where HCPs accept the risk (by writing purposeful medical reports). In doing so, opportunities for assistance talk and the associated benefits of doing so can be gained.

Sneaking off also describes the transformative descriptions of receiving a provisional green light from a Swiss AD association, suggesting potential therapeutic benefits that mitigate some of the reasons and intentions of a WTHD. From the moment applicants received a provisional green light, they felt back in control.

5.6 Chapter Summary

In this chapter, I have presented the main findings of my study, a critical thematic analysis of 24 people's experiences of seeking or being requested to provide medical documentation for use within an AD application. These 24 participants recalled 23 discrete attempts at applying for AD from the perspectives of nine applicants, ten family/friends of those who had already sought an assisted death, and five HCPs who received requests for documentation. I identified the pivotal experiences of refusal and a dilemma surrounding the decision about whether to disclose their reasons for seeking medical documentation. I subsequently developed two themes to characterize and explain the experiences and events reported by the participants.

The first theme of *the dangerous ground* captures a pervasive sense of risk and precariousness accompanying the disclosure of a WTHD while seeking medical documentation for use in an AD application. To help illuminate this, I articulated three sub-themes describing how disclosure of a WTHD was perceived as potentially unsafe. The first sub-theme, *losing control*, centred on the experiences of the power inequalities between requestors and HCPs, and how these were reinforced (to the detriment of the requestor). The second sub-theme, *mad or bad*, identifies a degrading heuristic surrounding the credibility of requestors following disclosure, entwined with the social stigma surrounding mental health and the personal moral judgments of HCPs. The final sub-theme, *feeling exposed*, described a distinctly regulatory threat that affected acts of assistance **and** disclosure.

Sneaking off to Switzerland followed to describe the furtive nature of seeking an assisted death. *Sneaking off* is characterized by practices of *being discreet*, utilized by requestors to circumnavigate *the dangerous ground* and gain access to medical documentation as a tactic to retain control over the application process. These practices of deception and avoiding detection are also seen to be employed by professionals utilizing their social power and knowledge to tacitly support

requestors. Finally, *sneaking off to Switzerland* also encompasses the transformative descriptions of receiving a provisional green light from a Swiss AD association, offering further insights into why AD was sought and suggest potential therapeutic benefits from being in control.

6 Discussion

6.1 Introduction

In the previous chapter, I presented two key themes that form the main findings of my study: *the dangerous ground* and *sneaking off to Switzerland*. In this chapter, I discuss the relevance of these findings alongside reflections on the limitations and impacts of my thesis. I begin by situating my findings within the existing literature on the discursive process of assisted dying (AD). To help make sense of and explain the implications of my findings further, I introduce and utilize the theoretical lens of ‘testimonial smothering’. In doing so, *sneaking off to Switzerland* can be identified as an act of self-silencing contributing to the reinforcement of the social stigma surrounding suicide that risks the marginalization of those holding a wish to hasten death (WTHD) yet further. I then finish by discussing the limitations, impacts and recommendations emanating from my study.

6.2 Situating *sneaking off to Switzerland*

To begin situating my findings within the wider literature and their relevance, it is worth revisiting my research question:

What are the experiences of those seeking or providing the medical documentation required as part of an application for an assisted death in Switzerland?

First and foremost, my findings seem congruent with those reported in the activist research carried out by the lobby group Dignity in Dying (Rilley and Heir, 2017). Much like their research, participants in my research also reported highly inconsistent reactions from healthcare professionals when disclosing their WTHD and the reasons for seeking documentation. Crucially, my findings provide evidence that people are being denied access to their medical records specifically because they seek them for use in an assisted dying (AD) application. Equally, the writing of medical reports for use in an AD application is happening, even when known that this may constitute a fitness to practise issue for General Medical Council registered and practicing doctors. What my study adds is that the subtle tensions between professional regulation and data rights discussed in chapter two (pointing out the subtle but important distinction between accessing medical records and the commissioning of specific

medical reports within professional regulation) does not seem to impact on seeking or providing documentation. Instead, the refusal of access to medical documentation – including following advice from medical defence organizations and the information commissioner’s office (ICO) – seems to devalue or disregard the data rights of patients, while the writing of medical reports happens purposefully and knowingly despite professional guidelines.

The experiences of being refused documentation, the obstruction of applications, and the blocking of assistance talk by HCPs within my findings are striking but not unique to the UK. Similar reports have been found within both prohibitive and permissive jurisdictions (Back et al., 2002; Starks et al., 2007; Gamondi et al., 2018; Hales et al., 2019; Byrnes, Ross and Murphy, 2022). Similarly, while regulatory fears were pervasive in my study, these are also not unique to my study as they are present throughout the literature on assistance talk. Medicolegal fears are not only experienced by those faced by responding to a WTHD within prohibitive jurisdictions; many studies have shown that existing fears can become replaced by newer ones related to permissive legislation when enacted (Haverkate et al., 2001; Van Marwijk et al., 2007; Otte et al., 2016; Patel et al., 2019; Variath et al., 2020; Byrnes, Ross and Murphy, 2022).

Sneaking off also complements previous findings from other studies surrounding the furtive nature of assistance talk within jurisdictions where AD is prohibited, notably in keeping with those studies that have already shown the importance of secrecy, lying, and strategic disclosure (Magnusson, 2002; Tomlinson et al., 2015; Gamondi et al., 2020). However, my findings do not, and cannot, go as far as Magnusson’s (2002) in describing the formation of an assistance underground nor do they seem to fully concur with Back et al (2002) who described the development of a “don’t ask, don’t tell” policy when it came to assistance talk. “Don’t ask, don’t tell” referred to not just a hesitancy to disclose a WTHD from a patient but a collusion between the patient and HCP which avoided the risk involved for both. While this was reported by one participant (HCP1) who utilized euphemisms to talk around the subject of providing a medical report, the bulk of the reports within my findings are of HCPs being unwilling to discuss a WTHD following disclosure. It is these experiences that are pivotal and those which are being passed onto others via advice not to disclose a WTHD and the reasons for seeking documentation.

It is to the issue of not disclosing a WTHD that I will continue to focus on with my findings also congruent with the suggestion from Richards (2016) that she (as a researcher) may have been the only avenue for assistance talk in the UK for some applying for an assisted death in Switzerland in her study. At the extreme end, two participants in my study recalled their loved ones receiving assisted deaths in Switzerland despite not once disclosing their WTHD to a single HCP here in the UK.

6.3 'Smothering' a WTHD

To help make sense of and explain *sneaking off to Switzerland* further, I find it useful to utilise Dotson's (2011) concept of *testimonial smothering* as a theoretical lens. Dotson defines testimonial smothering as "the truncating of...testimony in order to insure that the testimony contains only content for which one's audience demonstrates...competence" (p244).⁴⁹ Crucially, Dotson posits the truncation of testimony as a form of "self-silencing" utilized by speakers as a protective mechanism to avoid potential "social, political and/or material harm" (p244). Dotson argues that this is a form of coercive silencing, seen in exchanges where testimony is considered risky or unsafe for a (marginalized) speaker and where the (dominant) hearer demonstrates an inability or unwillingness to uptake their testimony.

It is *the dangerous ground* that descriptions of disclosure as risky and unsafe testimony are all-pervasive. Reports of being denied access to medical documentation were not the only events recalled within *the dangerous ground*, with other examples including: being diagnosed as depressed as an immediate response to disclosing a desire to seek the option of an assisted death, coerced care, obstruction to being referred onwards to other doctors, being shouted at, and being threatened with being reported to the police (and all within clinical encounters).

Where I see my findings offering a more distinct contribution to the literature on assistance talk beyond the insight of these practices also occurring here in the UK is within the sub-theme of *mad or bad*. This sub-theme seems to capture Dotson's argument that testimonial smothering stems from the hearer demonstrating a form of pernicious ignorance. This sub-theme is important as it suggests that it is not just poor care or communication skills (whilst present and relevant) nor the just the regulatory environment that contributes to creating a sense of precariousness surrounding the disclosure of a WTHD. Instead, an additional oppression seems to function based on people having **these** specific thoughts, desires, and ideas and wanting to discuss them with an HCP. Specifically, a disclosure of a WTHD risks the requestor's credibility (because they **must** be mad) or their moral character being questioned or undermined. I think this point goes underrecognized as an important driver within the motivations for those campaigning for permissive legislative change here in the UK. Simply put, people are resisting their experiences of being labelled *mad or bad*.

The resulting implication I fear from *mad or bad* is the implicit reinforcement of the social stigma associated with suicide and, in essence, contributing to re-stigmatizing suicide. The message being

⁴⁹ Insure, and not ensure, is used in the original.

propagated seems to be that assistance is *mad or bad* because it is assisting to do something that is *mad or bad* or undesirable. If ending your own life was not seen as something taboo nor would assistance. Yet, intimating a WTHD as irrational, incompetent, or illegitimate can undermine the credibility of people who hold a WTHD and invalidates their voices (Baril, 2020). Equally, people coming from positions supportive of permissive legislation change can further exacerbate the stigma of mental illness in resisting any labelling connected with suicide. As such, I would argue that any debate on terminology surrounding AD only seems to offer a zero-sum outcome for anyone seeking to improve the experiences of those holding a WTHD, whether from a preventative or pro-choice perspective (although this dichotomy risks reinforcing these as mutually exclusive categories which they are not likely to be in practice) (Marsh, Winter and Marzano, 2021). The social power relations seen to be reinforced within this sub-theme are of HCPs as **protectors** of the *mad or bad* (Winnington, 2016). Instead, Baril (2020) suggests avoiding (what he terms) “suicidism” which *mad or bad* seems to reflect, describing instead an ethics of care orientated focus prioritizing living beside those with a WTHD who may or may not decide to take up an option of assistance. These points form the basis of the common ground between those who disagree on the rights and wrongs of the legislative status quo.

What concerns me here are the implications of requestors subsequently smothering a WTHD and *sneaking off to Switzerland*. Blease et al. (2022) argues that an inability to access medical documentation is an injustice that prevents people gaining healthcare benefits and is one likely to disproportionately affect marginalized populations. In a similar fashion, the reports of active obstruction from some HCPs preventing patients from seeing other HCPs in my findings could detrimentally impact the potential for diagnosis, treatment, and even the addressing of the reasons for an applicant’s suffering. In thinking of the discursive triad at the heart of assistance talk, it is also important to point out that *sneaking off* does not just affect requestors. Instead, my findings sit alongside those international studies showing that the secrecy surrounding AD compounds the emotional burden on family members which furthers their social isolation following bereavement (Back et al., 2002; Starks et al., 2007; Gamondi et al., 2019). As such, *sneaking off* stands in stark contrast to the possibility of creating, affirming, or strengthening social bonds and relationships that comes with disclosure of a WTHD (Buchbinder, 2018; Norwood, 2020). With the strategic direction for medical records becoming more readily accessible through electronic access, I am left to wonder if the role of the HCP as an independent and expert third party discussing a WTHD with a requestor may become more rarefied as the ability to circumnavigate one aspect of *the dangerous ground* becomes easier. Whilst electronic access to medical records has the potential to be transformative to the inherent power imbalance between patient and doctor, the potential for avoiding a discussion about

a WTHD misses out on an opportunity for important conversations that might otherwise happen if it were not for a request for documentation (such as with A4 who withdrew their scheduled assisted death after obtaining new accommodation, or HCP3's patient who had misconceptions about benign tumours).

6.4 Limitations

6.4.1 Research methods

I encountered several problems during my research that stemmed from my protocol prioritizing anonymity for participants. Firstly, the anonymity I could offer participants was limited due to the logistical need for some identifiable information, such as a telephone number or an address. While this issue had minimal impact on my research, it highlights a possible limitation of my methods that may be relevant for other researchers researching sensitive or illegal topics. For example, government agencies will likely possess communication surveillance techniques that could easily identify the source of incoming phone calls or emails. In this sense, my research protocol felt more like how a journalist may seek to protect their sources rather than academic research.

On the other hand, the anonymity I could provide could cause problems for the trustworthiness of the data. Specifically, my research became at risk of including 'imposter participants'. Imposter participants are described by Ridge et al. (2023) as participants in research by people who are not who they claim to be. While Ridge et al. (2023) centre their concerns on the incentivization offered for participation in studies, I was concerned about zealous AD activists (regardless of whether supportive or oppositional) participating with a malign or ideological intent to steer the findings of my research. In this regard, I feared purposefully invented stories rather than recollections of, or reflections on, real events.

I had one interaction during the recruitment phase when one-person phoned claiming interest in participating. I initially reflected on this interaction as an example of a poor researcher-participant relationship, as the conversation did not flow as naturally. There may have been many reasons, not least my inadequacy as a novice researcher in creating an environment for the potential participant to feel at ease to discuss their experiences. Yet, I was immediately suspicious of the euphemistic and antagonistic questions and answers from the caller, which were so at odds with the immediately

recallable and detailed thoughts and memories of every other contact I had received, including with those who disagreed with the focus of my topic⁵⁰.

In similarity to the possibility of dishonesty by imposter participants, the potential for researcher dishonesty was also a limitation of my protocol. I had free reign to edit transcripts, and despite four transcripts being checked by one of my supervisors (JI), no recordings exist as proof of this data. Despite making efforts to improve the trustworthiness of the analysis, the data itself could easily have been manipulated, so this limitation would need a further step of oversight if my protocol were to be replicated.⁵¹

Lastly, whilst I had considered the possibility of breaking confidentiality within my protocol in regards to safeguarding participants, I did not account for the possible tensions created by hearing about some troubling recollections of unprofessional practice. This highlights yet another layer of being a dual GMC registered doctor and researcher, with duties bound by *Good Medical Practice* (GMC, 2013a). Future patient safety or wellbeing could be at risk if the reports of threats, coercion, and degrading treatment the participants described are repeated with others. It would be advisable for future researchers within sensitive topics to be fully aware and prepared that unprofessional behaviours by HCPs may be disclosed by participants. My anonymity protocol prevented identification of the identities of not only my participants, but of also their healthcare professionals who were being talked about. The advantage that this provided participants in knowing they were not going to get their HCPs in trouble resulted in the inability to challenge these HCPs and their behaviours (not only on behalf of/with the participants but also for future patients). A suggestion would be to include a statement in the participant information sheet along the lines of “if unprofessional or unethical practice comes to light, then the researcher will seek consent to report this, asking for deanonymized details of the event with the participant having the right to provide/withhold consent for this to occur”. The crucial aspect of consent by the participant would also help redress my concerns/the inherent power imbalance within my research regarding my choice for a blanket policy when it came to anonymity.

⁵⁰ This raises an additional point about how I missed out on the opportunity to include much more data from within these phone calls expressing interest in participating. I had not thought about this beforehand, and it would have required the inclusion of a mechanism to take consent for inclusion.

⁵¹ One such technique of improving the trustworthiness of the data could be using multiple transcribers, each checking the other’s work before the deletion of the recordings and then locking the documents so that they are not editable.

6.4.2 Critical credibility

Research credibility has specific meanings within qualitative research, first being described by Lincoln and Guba (1985) as the 'truth-value' of the research findings. Stahl and King (2020) supplement this by describing credibility as being how congruent qualitative research findings are with reality. It is from Stahl and King (2020) that I take credibility to refer to how plausible my findings are, especially in the eyes of the participants. It is here that a significant limitation of my protocol is encountered, which stems from the snapshot nature of a one-off interview and my inability to recontact the participants. Some of the interviews were very emotional for participants, yet my protocol offered no recourse for a proactive follow-up by myself to check on their welfare. Instead, these interviews sometimes felt like a smash-and-grab of data, at odds with the depth of emotion shared. Crucially, the lack of ability to follow-up with participants also meant a lack of ability to perform 'member-checking' (Lincoln and Guba, 1985; Birt et al., 2016), where I could have had the opportunity to discuss my analysis with the participants as a way of assessing how plausible my findings are.

A further limitation is that the experiences discussed could not be triangulated within the triad that I have defined as involved in assistance talk (requestors, their loved ones and their healthcare professionals). The recollections of events are (except for one interview) told by one person, the perspective of the others who were involved in the discussion are not represented. This issue becomes more pertinent when considering recall bias, especially so with the friends/family/loved ones or healthcare professional participants (FF in the interviews) who were sometimes recalling events up to two to three years ago (and even possibly longer).

Another limitation lies in the absence of public and patient involvement (PPI) throughout my thesis, notably a lack of PPI in developing my protocol and topic guides. When developing my protocol, I assumed that the small target population for my recruitment meant that I would not be able to utilize PPI. This lack of insight into other related avenues of PPI and utilizing stakeholder expertise was a significant oversight that could have added depth before and after the interviews⁵². As such, an increased orientation towards co-production could have strengthened my claims at taking a critical approach by utilizing insights from those with experience from the site of struggle.

⁵² Next time, I will consider utilizing similar patient populations. These populations could have been defined on many different characteristics, such as those who held a hypothetical WTHD or had sought/requested documentation from HCPs within other ethically contentious issues.

The experiences of HCPs facing requests to provide documentation feels as if it lacks the required information power (Malterud, Siersma and Guassora, 2016), with only five HCP participants. It is important to reflect that I am certainly not alone when it comes to problems in recruiting HCPs, and especially GPs, for qualitative studies (Parkinson et al., 2015; Patel, et al., 2017; Richell, 2020; Browne et al., 2022). In hindsight, I do wish I had researched barriers and facilitators to GP recruitment before recruitment and not afterwards. While the HCP participants added significant data, I felt that more were needed to further explore codes relating to safe disclosure, the purposeful taking of regulatory risk and furtive practices. In this respect, I did not feel I reached a level of information redundancy (Lincoln and Guba, 1985; Braun and Clarke, 2019) during coding.

Balancing out these limitations surrounding credibility are the examples of co-construction within my analysis. Notably, the sub-themes *mad or bad* and *being discreet* were developed and emerged from the voices of the participants and demonstrated the benefits of using semi-structured interviews and a critical theoretical framework. Similarly, my choice of a critical methodological approach was consistent with how many participants were motivated to participate by a desire to try and help improve the situation for others who may face similar experiences.

6.5 Impacts

I have achieved three notable impacts from my research so far. Firstly, I wrote an article in the *British Journal of General Practice*, clarifying the importance of the subtle distinction made by the GMC within its guidance between medical records and medical reports (Teed, 2017). Secondly, I sent a written submission to the Health and Social Care Committee inquiry into assisted dying, highlighting my findings (Teed, 2023). This inquiry is expected to publish its report in 2024.

Lastly, and most importantly, I was sufficiently concerned by the experiences of FF1 to contact the Information Commissioner's Office (ICO). To recap, FF1's parent had been refused access to their medical records despite making a subject access request, with the reason for the refusal being that they sought to use their medical records within an application for the option of an assisted death in Switzerland (Section 5.4.4, page 91). They had been informed of the results of a crucial scan which revealed pathology but were subsequently refused a hard copy of the scan report. FF1 recalled phoning the ICO and being told by a call handler that the doctor was entitled to refuse access.

I contacted the ICO to question this advice. Yet, I too, received the same advice from a senior case handler at the ICO that providing access to medical records in this scenario could constitute serious

harm and that Article 5 (1) of the *Subject Access Modification (Health) Order 2000* applied. This advice conflicted with my understanding of data rights. It seemed to create a scenario where the ICO derogated its powers to the doctor whether serious harm could occur and ceased providing a regulatory oversight of the doctor's reasoning. In effect, FF1 could not appeal this refusal, so I challenged this further with the ICO and the GMC by sending requests under the Freedom of Information Act 2000 to the ICO and the GMC.

From the ICO, I requested if they had any guidance or policy on subject access requests when seeking documentation for use in an application for an assisted death. They did not, but they did send me (redacted) details of decisions where they had responded to refusals to give access to medical records due to the likelihood of causing serious harm under Article 5 (1) of the *Subject Access Modification (Health) Order 2000*. While these decisions were case-specific, the ICO had repeatedly found that where information had already been disclosed to a person in one form, withholding the information in other formats was not deemed to be justified. After a further appeal to the ICO (after the GMC refused to share the legal advice they received on accessing medical records when used for AD applications), they contacted the GMC themselves. While my freedom of information requests were all denied, they did achieve the result of the ICO and the GMC discussing the issue. Subsequently, I received this communication from a senior case officer at the ICO:

“Any doctor is obliged to comply with a subject access request unless it is likely to cause serious harm to the patient. It was my initial view that suicide clearly constituted harm, however after considering all the information at my disposal it appears that the issue of harm would only be likely to arise if the patient was **unaware** of any documented medical condition...as a result of this case I have approached our data protection department to consider reviewing our guidance on SARs (Subject Access Requests) made to GPs” (emphasis in original) (Personal communication, 2020)

The importance of this communication is how it corresponds with and clarifies the previous decisions the ICO has made regarding how the serious harm test is applied in practice. The subtle distinction about whether a person has already received the information (or not) in one format (including verbally) affects whether the serious harm test can be applied to withholding access in another format.

After completing my thesis, communicating this subtle distinction to a wider audience will be my first act, likely consisting of a further article in the *BJGP* in the first instance.

Getting the ICO to discuss the regulatory background of my research with the GMC to clarify their guidance is already my proudest achievement emanating from my research. However, I need to find out if this was acted upon or whether this has made any real difference to subsequent ICO advice/decisions. I will also disseminate my thesis to medical defense organizations and Swiss AD associations to discuss these issues and help them advise their members on the details of data rights in the UK, which leads neatly to my recommendations.

6.6 Recommendations

The aims of my recommendations are to contribute to the de-escalation of fears that HCPs may have about providing medical documentation, even out inconsistencies in care, and ensure that applicants gain access to the documentation that they are entitled to receive.

6.6.1 Regulatory coordination

Greater coordination and information sharing are needed at an organizational level between the relevant regulatory stakeholders surrounding the provision of medical documentation. I take these stakeholders to include, at minimum, the GMC, the British Medical Association (BMA), the Royal College of Nursing (RCN), medical defence organizations and the ICO, as well as the professional bodies that represent or register other healthcare professionals that write reports.

This coordination would aim to standardize and improve the guidance provided by all organizations, particularly that given by medical defence organizations and the ICO. The ICO needs to go beyond “considering” reviewing their guidance on SARs and actively ensure call handlers and case officers are appropriately informed of the data rights of individuals seeking access to their own medical information. As shown by my research, requestors are already in a precarious position; challenging the ICO takes energy, resources, and, crucially, time (that they may not have). Additionally, the ICO should provide further guidance surrounding the serious harm test in Schedule 3, Part 2 of the *Data Protection Act 2018*. *In turn*, medical defence organizations need to urgently review the advice to their members to ensure that it accurately reflects the regulatory background, particularly the data rights of individuals, which professionals have a duty to uphold. This advice should include linking to the

serious harm test and the crucial yet subtle importance of whether an individual has already received the information verbally.

6.6.2 GMC guidance

The GMC should consider providing further information within their guidance *When a patient seeks advice or information about assistance to die* (GMC, 2022) to make the issue of the provision of documentation clearer and more distinct from acts of assistance. Clause 6a states, “Doctors should...be prepared to listen and to discuss the reasons for the patient’s request” (GMC, 2022). I would recommend changing this to: “Doctors should be prepared to listen and discuss the reasons for the patient’s request. For the avoidance of doubt, discussing the reasons for the patient’s request constitutes *Good Medical Practice*”. I would recommend an additional paragraph similar in construction to that seen in the British Medical Association’s guidance *Responding to patient requests for assisted suicide* (BMA, 2021), which is unambiguous in promoting the positive data rights patients have regarding access to their medical records:

“Where a patient makes a subject access request doctors are obliged to provide the requested information in order to satisfy their obligations under the GDPR. This is so regardless of whether the doctor knows or suspects that the medical records may be used abroad for assisted dying” (BMA, 2021)

I also recommend the addition of how the GMC makes a regulatory distinction between providing access to medical records (as per data rights) and the writing of medical reports (which could lead to a fitness to practise review). This distinction is currently buried in the clauses of a document intended for fitness to practise case examiners and yet needs more prominence.

The GMC should also highlight that refusing to discuss the reasons behind a WTHD or provide access to medical records based on a doctor’s personal beliefs (conscientious objection) creates duties on the doctor as detailed in *Personal beliefs and medical practice* (GMC, 2013b). These duties include telling the patient that they have a right to see another doctor who does not hold the same objection and ensuring that the patient has enough information to arrange an appointment with them (GMC, 2020).

6.6.3 Further research

The participants in my study, and the communities they belong to, are forging ahead with new therapeutic tools and understandings that they know they could benefit from. The effect of receiving a provisional green light reported by the participants in my study warrants further research. Offering the option of (assisted) death as a therapeutic tool is highly contested, yet there seems to be a scarcity of evidence informing the matter. Like Price et al. (2011), most research on this issue seeks to assess the existence and strength of a WTHD over time in a given population, but with little focus on the experience and effects of receiving a provisional green light (or equivalent). With the increasing number of jurisdictions legislating permissively in one form or another, exploring this phenomenon should be possible without ethical constraint. It seems pertinent to ask whether receiving the option of an assisted death results in measurable therapeutic effects (psychological or physical). Framing assistance talk as a discursive process also means seeking to identify who these effects may impact, such as all those identified as being involved, and how.

The aesthetics of assisted death is another avenue of research that could reveal interesting insights into new relational understandings of AD. I feel a focus on the aesthetics of AD would be particularly ripe for a wide variety of disciplines, methods and methodologies exploring and explaining the choices made within these newly emerging social events.

On a personal level, I would like to spend my subsequent efforts exploring the epistemic components of understanding AD as a discursive process. Specifically, I would like to follow on from my findings in my thesis of the self-silencing of a WTHD to explore how someone who receives a request can work to ensure that the disclosure encounter is epistemically just. This is something Verkerk (2015) states that she seeks to achieve in her work as a GP in The Netherlands when receiving requests for assisted dying. It would be her descriptions of a reflective practice concerning the moral discourse surrounding disclosure that I would take as a starting point and then widen it to include the requestor-family-HCP triad that better describes the discursive practice of assistance talk.

6.6.4 Healthcare professionals

The primary advice I would give to any professional encountering someone seeking an assisted death in Switzerland is merely to reiterate *Good Medical Practice*. Discussing someone's reasons, meanings, and intentions for seeking an assisted death is part of *Good Medical Practice*. As HCP5 stated within my research, doing so "is absolutely a normal day's work" and the focus of the encounter should be the care of your patient. Above all, I would counsel against imposing a personal moral framework upon a patient uninvited following disclosure of a WTHD, as this could irreparably damage the therapeutic relationship. A HCP's personal opinions on the desirability of permissive legislation (or not) probably matter less to the patient than being listened to, respected, and assessed as an equal in a collaborative exchange. Again, this is already *Good Medical Practice*.

Refusing access to medical records, which a patient is entitled to in law, needs a reasoned articulation beyond what they may (or may not) do with their information. Invoking a serious harm rationale for refusing access to medical records seems more appropriate to scenarios surrounding the disclosure of **new** information (i.e. that the patient does not yet know) that may subsequently cause harm to the patient or another, for example, providing information within medical records that breaks the confidentiality of another patient. If the medical information is already known to a patient, such as via verbal communication from another HCP, serious harm is unlikely to be caused and the serious harm test is unlikely to be an applicable reason to withhold access to medical records.

I would also advise being astute to the use of euphemisms surrounding AD, most notably about "plans", "making arrangements", or the probing of personal opinions on subjects surrounding the topic. The use of euphemisms and probing for a HCP's personal views on moral matters likely form part of a patient's risk assessment about whether they feel safe disclosing their WTHD.

As for writing medical reports, my opinion in reading the GMC guidance would be that although writing a specific medical report for use in an AD application could invite a fitness to practise review for doctors with a potential for a criminal investigation, there is important context to consider. Not least, those who seek the option of an assisted death abroad are in the minority, and so any single HCP is unlikely to encounter multiple applications. As such, creating a singular medical report that does not seek to obfuscate or be dishonest and keeps to objective facts is likely an act that falls within the GMC factors that tend against professional sanction. Conversely, a doctor who sets out to purposefully deceive and does so repeatedly over the course of the creation of multiple reports for different people within a private practice profiteering from these reports will find that their acts are those that tend towards professional sanction.

6.7 Summary

In this chapter, I have discussed the relevance of my findings by identifying *sneaking off to Switzerland* as an act of self-silencing (testimonial smothering). Self-silencing is in one sense coerced due to the experiences of participants within *the dangerous ground*, but also an act of forging new therapeutic tools and understandings that they, and others like them, may benefit from. The implication I fear from my findings is the reinforcement of the social stigma surrounding suicide and those who hold a WTHD. Reducing this stigma is the urgent middle ground within the regulatory status quo.

I also discussed the limitations of my research protocol and how this would need to be improved if replicated by others, not least for research trustworthiness. However, my research has achieved collaboration between the GMC and the ICO regarding patient data rights, which may yet achieve my goal of helping improve the overall situation for patients and HCPs. It is to the subtleties within data rights that further advice can be given to HCPs who may face a request for documentation for use in an AD application, and what I will be my first objective following this.

7 Summary

I began my research journey in 2016 by identifying the fact that despite assisted dying (AD) being illegal within all nations of the UK, doctors still faced the phenomenon in practice via requests to provide medical documentation. Citizens of the UK require this documentation as part of the application process for an assisted death in Switzerland, stemming from the requirements for Swiss AD associations to comply with Swiss criminal law, in which assistance is only prohibited if the assistor is motivated by selfish reasons. While giving copies of medical records is not deemed a fitness to practise issue by the General Medical Council (GMC), even if the doctor knows that they will be used in an AD application, writing specific medical reports may well be and may constitute a crime under the *Suicide Act 1961* within England and Wales. Crucially, healthcare professionals (HCPs) are uniquely named within the factors that tend towards prosecution within Crown Prosecution Service (CPS) guidelines.

Subsequently, general practitioners (GPs) have reported fear and uncertainty about balancing regulatory guidance regarding AD and the patient's data rights (Pulse, 2012) within the *Data Protection Act 2018*. However, these rights are tempered by the empowerment of HCPs to withhold access to medical records if this could cause serious harm to the individual or others. These powers are crucial in understanding of AD as a discursive process (assistance talk), where those involved attempt to navigate the complexities and uncertainties of a wish to hasten death (WTHD) together. Crucially, seeking the option of an assisted death does not necessarily mean someone wants to or is seeking to die, but does highlight the importance of identity, agency, and control to them as individuals. Yet, assistance talk does not occur within a cultural vacuum; ethical considerations focus on who is included or excluded in the discursive process and the consequences of this inclusion or exclusion.

Reports from a lobby group suggested a possible site of assistance talk here in the UK, with some people reporting inconsistent care after disclosing a WTHD when seeking medical documentation for use in an AD application, including the denial of access to their medical records. With a gap in academic research on these experiences within the UK, my research question was: What are the experiences of those seeking, or providing, the medical documentation required as part of an application for an assisted death in Switzerland? Not only did I aim to illuminate an otherwise overlooked issue, I sought to provide recommendations that could contribute to de-escalating the reported fears and uncertainties of HCPs, even out inconsistencies in care, and ensure that applicants gain access to the documentation they are entitled to receive.

To recruit participants, I developed a novel research protocol that prioritized anonymity for potential participants from the first recruitment contact. This focus on anonymity meant paying attention to the details of the possible ways identity could be exposed within each step of my study. In practice, this was not completely achieved, with a logistical need for some form of identifiable information occasionally required (such as a telephone number or address). However, it did result in me traveling across the country to meet people face to face whose identities I did not know who they were and still do not to this day. As such, a lone worker policy was instrumental for my safety.

I interviewed a convenience sample of 24 people consisting of all those who were eligible and agreed to participate about their experiences of seeking or providing medical documentation for use within an AD application. These 24 people consisted of nine applicants applying for the option of an assisted death themselves, ten family/friends of applicants who had already sought medical documentation, and five healthcare professionals. These 24 people discussed 23 discrete AD applications as one interview consisted of a married couple discussing their attempts at getting documentation for only one of them.

I developed two key themes from these experiences. The first, *the dangerous ground*, captures a pervasive sense of risk and precariousness accompanying the disclosure of a wish to hasten death (WTHD) while seeking medical documentation. Disclosure risked being refused documentation, including copies of their medical records, the inability to continue with applying for an assisted death, and even experiencing the very deaths that they had sought to avoid in the first place. In seeking a greater sense of control over their death requestors, initially reinforced their reliance on HCPs. To kick up a fuss and challenge HCPs meant further exposing themselves and their applications for an assisted death.

Ultimately, *the dangerous ground* describes the disclosure of a WTHD when seeking medical documentation intended for use in an AD application as potentially unsafe testimony. The risks, injustices, and pre-judgments faced by requestors all followed uniquely from disclosure and all within the context of seeking information and knowledge about themselves/their health status as entitled to under data protection law. Reports of being denied access to medical documentation were not the only events recalled with other examples including being diagnosed as depressed as an immediate response to disclosing a desire to seek the option of an assisted death, coerced care, obstruction to being referred onwards to other doctors, being shouted at, and being threatened with being reported to the police (and all within clinical encounters).

One participant also reported phoning the Information Commissioner's Office telephone advice line after being refused medical records, only for the advisor to state that this refusal could not be challenged. I challenged this interpretation (and not the participant's case) with the ICO, eventually getting the ICO to liaise with the GMC. Subsequently, the ICO committed to consider reviewing their guidance on Subject Access Requests to include detail on what constitutes serious harm when providing access to medical records.

In the second theme, *sneaking off to Switzerland*, I describe the furtive nature of seeking the option of an assisted death in Switzerland. In the first instance, sneaking off describes a panoply of practices that aim to circumnavigate *the dangerous ground* as a purposeful strategy to retain control over AD applications. Trust in HCPs was lost in encounters involving a refusal and as such participants learned not to disclose or lie about their reasons for seeking documentation. *Sneaking off* can be understood as a form of self-silencing that as a result of the coercive *dangerous ground* and a heuristic of being judged as if *mad or bad* for holding a WTHD. It is this self-silencing and this heuristic that may act to reinforce the social stigma surrounding suicide, not least within terminological debates and label wrestling.

Sneaking off also encompasses recollections that beyond the non-disclosure of a WTHD: medical reports being written knowingly that it may be fitness to practise issue, the use of private medical appointments as a way of getting a medical summary, a Swiss AD association coaching people on their AD applications about what to write and not what to write, a UK coroner advising someone how to avoid an investigation into an assisted death in Switzerland, and reports being written by an osteopath and homeopath. The aim is for a requestor to receive a provisional green light from a Swiss AD association, experiences of which were described in therapeutic terms by my participants. It is these new therapeutic understandings that these networks are forging ahead with regardless of the regulatory background, and it is this response to receiving a provisional green light that needs further research.

Lastly, as I see in the new year of 2024, my thesis is still highly relevant and not just because of the regulatory considerations important within anticipated parliamentary votes on permissive legislation in Scotland and the crown dependencies. Just a few months ago I received a copy of a letter written from a GP to a patient refusing access to their medical records specifically because they sought the option of an assisted death in Switzerland. Seven years after I began my research journey, disclosing a WTHD and the reason for seeking documentation still comes with risks.

8 References

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9 Appendices

9.1 Appendix 1: Search Terms

PubMed

((((((((((((((((suicide, assisted[MeSH Terms]) OR euthanasia[MeSH Terms]) OR right to die[MeSH Terms]) OR assisted suicide[Title/Abstract]) OR assisted-suicide[Title/Abstract]) OR assisted dying[Title/Abstract]) OR assisted-dying[Title/Abstract]) OR assisted death[Title/Abstract]) OR assisted-death[Title/Abstract]) OR right to die[Title/Abstract]) OR hasten death[Title/Abstract]) OR wish to die[Title/Abstract]) OR desire to die[Title/Abstract]) OR rational suicide[Title/Abstract])) AND (((((((((((((((((patient[Title/Abstract]) OR patients[Title/Abstract]) OR "Professional-Patient Relations"[Mesh] OR doctor*[Title/Abstract]) OR physician*[Title/Abstract]) OR relation*[Title/Abstract]) OR rapport[Title/Abstract]) OR communicat*[Title/Abstract]) OR meaning*[Title/Abstract]) OR feel*[Title/Abstract]) OR experience*[Title/Abstract]) OR wishes[Title/Abstract]) OR decision[Title/Abstract]) OR decision-making[Title/Abstract]) OR dignitas[Title/Abstract]) OR lifecircle[Title/Abstract]) OR ex international[Title/Abstract])

Scopus

(TITLE-ABS-KEY("assisted dying") OR TITLE-ABS-KEY("assisted death") OR TITLE-ABS-KEY("assist dying") OR TITLE-ABS-KEY("assist suicide") OR TITLE-ABS-KEY("assisted suicide") OR TITLE-ABS-KEY("assistance to die") OR TITLE-ABS-KEY("assist to die") OR TITLE-ABS-KEY("aid in dying") OR TITLE-ABS-KEY("hasten death") OR TITLE-ABS-KEY("hastened death") OR TITLE-ABS-KEY("hastened dying") OR TITLE-ABS-KEY("hasten dying") OR TITLE-ABS-KEY("wish to die") OR TITLE-ABS-KEY("desire to die") OR TITLE-ABS-KEY("right to die") OR TITLE-ABS-KEY("rational suicide") OR TITLE-ABS-KEY(euthanasia)) AND ORIG-LOAD-DATE AFT 1724998266 AND ORIG-LOAD-DATE BEF 1725603064 AND PUBYEAR AFT 2022 AND (EXCLUDE (SUBJAREA,"VETE") OR EXCLUDE (SUBJAREA,"BIOC") OR EXCLUDE (SUBJAREA,"AGRI"))

(Including reference checking of all relevant results)

9.2 Appendix 2: CPS guidelines

Crown Prosecution Service policy for prosecutors in respect of cases of encouraging or assisting suicide (CPS, 2014).

Factors tending in favour of prosecution:

43. A prosecution is more likely to be required if:

1. the victim was under 18 years of age;
2. the victim did not have the capacity (as defined by the Mental Capacity Act 2005) to reach an informed decision to commit suicide;
3. the victim had not reached a voluntary, clear, settled and informed decision to commit suicide;
4. the victim had not clearly and unequivocally communicated his or her decision to commit suicide to the suspect;
5. the victim did not seek the encouragement or assistance of the suspect personally or on his or her own initiative;
6. the suspect was not wholly motivated by compassion; for example, the suspect was motivated by the prospect that he or she or a person closely connected to him or her stood to gain in some way from the death of the victim;
7. the suspect pressured the victim to commit suicide;
8. the suspect did not take reasonable steps to ensure that any other person had not pressured the victim to commit suicide;
9. the suspect had a history of violence or abuse against the victim;
10. the victim was physically able to undertake the act that constituted the assistance him or herself;
11. the suspect was unknown to the victim and encouraged or assisted the victim to commit or attempt to commit suicide by providing specific information via, for example, a website or publication;
12. the suspect gave encouragement or assistance to more than one victim who were not known to each other;
13. the suspect was paid by the victim or those close to the victim for his or her encouragement or assistance;
14. the suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional, a professional carer [whether for payment or not], or as a person in authority, such as a prison officer, **and the victim was in his or her care; [1]**
15. the suspect was aware that the victim intended to commit suicide in a public place where it was reasonable to think that members of the public may be present;

16. the suspect was acting in his or her capacity as a person involved in the management or as an employee (whether for payment or not) of an organisation or group, a purpose of which is to provide a physical environment (whether for payment or not) in which to allow another to commit suicide.

Footnote [1]: For the avoidance of doubt the words "and the victim was in his or her care" qualify all of the preceding parts of this paragraph [43.14]. This factor does not apply merely because someone was acting in a capacity described within it: it applies only where there was, in addition, a relationship of care between the suspect and the victims such that it will be necessary to consider whether the suspect may have exerted some influence on the victim.

Factors tending against prosecution

45. A prosecution is less likely to be required if:

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

9.3 Appendix 3: Recruitment call

RESEARCH PARTICIPANTS WANTED

**HAVE YOU EVER REQUESTED A MEDICAL REPORT OR COPY OF
MEDICAL RECORDS FROM A HEALTHCARE PROFESSIONAL TO HELP
ENABLE YOU TO HAVE AN ASSISTED DEATH* ABROAD?**

(* i.e. at 'Dignitas' or 'Eternal Spirit Foundation' in Switzerland)

or

**ARE YOU A HEALTHCARE PROFESSIONAL WHO HAS EVER RECEIVED
A REQUEST FROM A PATIENT FOR A MEDICAL REPORT OR COPY OF
MEDICAL RECORDS AS THEY WERE SEEKING AN ASSISTED DEATH
ABROAD?**

IF SO, CAN YOU HELP US LISTEN TO AND UNDERSTAND YOUR EXPERIENCES?

THIS RESEARCH WILL EXPLORE THE EXPERIENCES OF PATIENTS AND DOCTORS DURING THESE
REQUESTS

ALL CONTACT WILL BE STRICTLY ANONYMOUS

To find out more information please visit:

www.AssistedDyingResearch.wordpress.com

PLEASE PASS THIS INFORMATION ON TO ANYONE YOU MIGHT KNOW WHO MIGHT BE ABLE TO HELP

9.4 Appendix 4: Recruitment phone call log sheet

CALL NUMBER:

PSEUDONYM:

READ WEBSITE: YES / NO

KNOWN TO ME: YES / NO

PATIENT

OVER 18: YES / NO

REQUESTED MEDICAL DOCUMENTATION SINCE 1998: YES / NO

RECEIVE REPORT/OTHER EVIDENCE: KNOWINGLY/REFUSED BUT RECEIVED OTHER MEANS/REFUSED

AGE GROUP: 18-39 40-49 50-59 60-69 70-79 80-89 90-99 100+

GENDER: MALE / FEMALE / OTHER

ETHNICITY:

GEOGRAPHIC LOCATION:

FAITH:

UNDERLYING CLINICAL CONDITION:

DOCTOR

RECEIVED REQUEST FOR MEDICAL DOCUMENTATION: YES / NO

ON SPECIALTY REGISTER AT TIME: YES / NO

AGE GROUP: 18-39 40-49 50-59 60-69 70-79 80-89 90-99 100+

GENDER: MALE / FEMALE / OTHER

ETHNICITY:

GEOGRAPHIC LOCATION:

CLINICAL SPECIALTY:

FAITH:

PLAN

WHERE BEST/WHEN?

FOLLOW-UP

How feeling? Any questions? Thoughts of the future?

Signpost to support if needed

9.5 Appendix 5: Topic guides

9.5.1 *Applicants and family/friends*

Reasons

Maybe we could start with what led you to requesting a medical report from your doctor and why?

Prognosis/underlying clinical condition? Care received before request.

The Encounter

Can you describe what happened when you asked your doctor for the report? How did it happen/did you know the doctor?

What was talked about? Were reasons talked about and what do you remember was spoken about them?

How did it feel? Language used?

What do you think or feel about your relationship with the doctor and their role? Did it affect your relationship? Trust?

Did you/do you know the law governing these reports?

Emotional Support

How did it affect you?

Did you talk about this with anyone, before, during or afterwards? Family? Friends?

Implications

What were the implications personally and pragmatically to the granting/refusal?

Decision-Making

Why do you think the request was granted/refused? What was important?

How do you feel about the process of deciding?

Ethical

“Some people might say...do you think these concepts were discussed at all?”

‘Pro’: Autonomy (and lived experience), suffering, upfront discussion/safeguards, financial, ‘right-to-die’

‘Opposed’: do no harm, killing, slippery slope, pall care can alleviate (e.g., pain, dignity)/well-being in illness, depression,

Vulnerability – do you think you are vulnerable? Age, disability?

FINISHING REMARKS

Thank you/questions/signpost to support if needed

9.5.2 Healthcare professionals

The Encounter

Maybe we could start with you describing what happened?

What was discussed? Were reasons talked about and what do you remember was spoken about them?

How did it feel?

What do you think or feel about your relationship with the patient and their role? Did it affect your relationship?
Trust?

The Patient

Had you known them long?

Prognosis/underlying clinical condition – any thoughts about that?

Narrative?

Emotional Support

How did it affect you?

Did you talk about this with anyone, before, during or afterwards? Family? Friends? Do you feel supported?

Do you know of others who have faced these dilemmas? Do you know if they granted/refused?

Implications

Defence union? Advice?

What were the implications personally and to the patient in the granting/refusal?

How did you think the patient take it?

Decision-Making

Why do you grant/refuse the request? What was important?

Do you know about GMC guidance/law/BMA advice. Did these play a part? What do you think about them?

Ethical

“Some people might say...do you think these concepts were discussed at all?”

‘Pro’: Autonomy (inc lived experience), control, suffering, upfront discussion/safeguards, financial, ‘right-to-die’, paternalism, compassion, justice (cost)

‘Opposed’: just ADRT, do no harm, loss/disability, killing, slippery slope, pall care can alleviate (e.g. pain, dignity), depression, cross Rubicon, death anxiety

Vulnerability – do you think the patient was vulnerable? Age, disability paradox, response shift theory

FINISHING REMARKS

Thank you/questions/signpost to support if needed

9.6 Appendix 6: Motivations for seeking assisted dying

REASONS	LINE-BY-LINE EXAMPLES
Physical and mental suffering	<p>“All the symptoms are getting worse all the time”</p> <p>“I don’t have to suffer pain”</p> <p>“Consumed by it one hundred percent of the time”</p> <p>“Everything is always constant pain”</p> <p>“It has become unbearable”</p> <p>“Not the destination, but the journey”</p> <p>“It’s the worst kind of existence”</p>
Fears of future suffering	<p>“He was very scared how he would die when he got to end stage MND”</p> <p>“She was frightened of the way she would die”</p> <p>“Condemned to a life of torture”</p> <p>“Not frightened of death, but the way she would die”</p> <p>“Fear of it being painful”</p> <p>“Only going to get worse”</p> <p>“The thought of choking/suffocating”</p>
Fears of dependency	<p>“Didn’t want to be entirely dependent”</p> <p>“Don’t want people looking after me”</p> <p>“Not afraid of dying, but being unable to move”</p> <p>“I don’t want to be a vegetable, unable to speak or move”</p> <p>“Don’t want the care”</p> <p>“Being bed bound is worse than death”</p>
Fears of suicide ‘going wrong’	<p>“I’m so terrified of getting it wrong”</p> <p>“It might not work, might end up a damn site worse”</p> <p>“As far as I know it can’t go wrong if you go to Dignitas”</p> <p>“I’ve tried a few times already”</p> <p>“I’m just too scared to do it myself”</p>
A desire to avoid burdening others	<p>“Didn’t want to be a burden”</p> <p>“She didn’t want to put us through looking after her with Alzheimer’s”</p> <p>“I don’t want for you to have to care for me”</p> <p>“My friend can have her life back”</p>
A ‘good’ death	<p>“It’s about going with grace”</p> <p>“It all seems very lovely (at Dignitas)”</p> <p>“A peaceful way”</p> <p>“Quick and peaceful”</p> <p>“Positive experience of Dignitas already”</p>
Control	<p>“No control over his death. He was concerned about that”</p> <p>“I know right up until the end I am in control”</p> <p>“It was a matter of having the certainty of how it was going to happen”</p> <p>“It’s about uncertainty”</p> <p>“She didn’t want the lack of control”</p> <p>“The loss of control was hard”</p>
Autonomy	<p>“Only one person has got a say in this matter and that’s me”</p> <p>“I could choose my time”</p> <p>“I know myself better than you”</p> <p>“I dictate what goes on”</p> <p>“I am of sound mind”</p> <p>“It’s my life”</p>

9.7 Appendix 7: Coding structure

THEME	SUB-THEME	CODES
<p>1. The Dangerous Ground Captures a pervasive sense of risk and precariousness accompanying disclosure of a WTHD when seeking documentation.</p>	<p>Losing control</p>	<p>NOT KNOWING MEDICAL POWER FEAR OF POWER BEING PREVENTED SURRENDERING TO A SYSTEM BEING REFUSED SUICIDE BAD DEATHS</p>
	<p>Mad or bad</p>	<p>WON'T DISCUSS TREATED LIKE SHIT BEING JUDGED MAD BAD CREDIBILITY STIGMA LABELS</p>
	<p>Feeling exposed</p>	<p>LEGAL POWER LEGAL THREATS POLICE INVOLVEMENT CAN'T DISCUSS GETTING ADVICE PROTECT CAREER THINKING OF THE DOCTOR</p>
<p>2. Sneaking off to Switzerland Captures the furtive nature of seeking an assisted death abroad and why.</p>	<p>Being discreet</p>	<p>BEING DISCREET NO RECORD OFF THE RECORD LOSS OF TRUST REGRET STOPPED TELLING DON'T TELL TELLING EVERYONE SAFE DISCLOSURE DR SHOPPING REPORTS</p>
	<p>In control</p>	<p>THE GREEN LIGHT KNOWING HELPS REASONS EXPERIENCES OF AD CONTROL CHALLENGE BELIEFS BURDEN LIFTIING</p>

9.8 Appendix 8: Mental capacity report

[REDACTED]

[REDACTED] 2018

Dignitas
PO Box 17
812 Forch
Switzerland

Dear Sirs

[REDACTED]

I write to confirm that [REDACTED] consulted me on [REDACTED] for an assessment of his mental state with particular reference to his capacity of judgement in respect of his wish to access your service of an accompanied suicide. I can confirm that I am a medical practitioner with specialist qualifications in the Assessment and Diagnosis of Mental Disorder and am on the Specialist Register of the General Medical Council. My expertise includes Assessment of Mental Capacity of Judgement.

[REDACTED] was accompanied by his wife throughout the consultation. He gave a detailed account of his life, both from the family and career perspectives as well as detailing his past medical history. In [REDACTED] and after neurological assessment and investigations was diagnosed with Motor neurone disease (amyotrophic lateral sclerosis) and given a prognosis of six - 24 months. He is currently under the care of [REDACTED]

[REDACTED] He estimated the benefits of these treatments to be modest at best.

The progression of Motor neurone disease is divided into three phases as follows:

Phase 1: One can still do everything but a number of things are becoming progressively more difficult.

Phase 2: Some of the activities of daily living can no longer be done.

Phase 3: The 'death phase' in particular when respiratory muscles begin to weaken.

[REDACTED] estimated that he was entering phase 2 and gave a number of instances supporting this view i.e. he has had to give up [REDACTED]. The weakness in both hands means he has trouble opening bottles and is requiring increasing assistance in putting on his jacket. He is

[REDACTED]

otherwise still able to dress himself and use a computer and is able to walk. He gets much more tired than he previously did and now needs a sleep in the afternoons. The normal activities of daily living are all taking much longer than previously.

_____ has enjoyed good mental health throughout his life _____

My assessment of _____ mental state revealed a euthymic mood in an individual who was fully cooperative and open throughout the interview. There was no evidence of disturbance of thinking either in terms of form or content and no psychotic phenomena such as hallucinations and passivity experiences were observed/elicited. He was fully oriented in time and place and his immediate recall and knowledge of recent events was excellent.

In terms of his mental capacity of judgement, we discussed at length his request to access the service of an accompanied suicide at Dignitas. He first approached you in early 2017 about your service. He and his wife have given this much thought since initially doing so and he has remained resolute in his view in applying for a provisional Green Light. He wishes to have the option to accelerate his death at a time of his choosing in order to avoid what is likely to be a very unpleasant, lingering death both for his own sake and for that of his family. In very practical terms he feels that it is a tremendous waste of resources providing carers and other support services in order to maintain a life that is devoid of any quality. He feels that being granted a provisional Green Light will allow him to focus on maximising the remaining quality time he has with his family rather than living in fear of what the future holds in terms of prolonged suffering and distress.

_____ is a highly intelligent individual who has a full understanding of the process involved in an accompanied suicide. He has read your website in detail along with the information you have sent to him. He demonstrated an ability to retain this information which is more than sufficient for him to make an informed judgement about the process and the outcome. It was very clear at interview that this decision was very much his own and had not been made under duress or influence from anyone else including his wife. She is obviously incredibly supportive of his decision but at the same time understandably distressed. In addition he has been very open with members of his family and close friends about his commitment to this decision. No one thought this to be in anyway irrational or ill-informed.

In summary I am of the very strong professional opinion that _____ does indeed have full mental capacity of judgement in respect of the specific decision to access your service of an accompanied suicide. Please accept this report in support of his request to obtain a provisional Green Light. Finally he is fully aware that up to 70 percent of people who are granted a Green Light do not proceed with an accompanied suicide.

If I can be of further assistance please do not hesitate to revert to me.

Yours faithfully

FRCPsych
Consultant Psychiatrist