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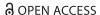
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## Assisted Suicide as a Remedy for Suffering? The End-of-Life Preferences of British "Suicide Tourists"

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#### **ABSTRACT**

The highly charged debate about the moral status of assisted suicide features regularly in the news media in medically advanced countries. In the United Kingdom, the debate has been dominated in recent years by a new mode of death: assisted suicide in Switzerland, so-called suicide tourism. Drawing on in-depth interviews with people who were actively planning on 'going to Switzerland,' alongside participant-observation at a do-it-yourself self-deliverance workshop, I discuss how participants arrived at their decision to seek professionalized assistance. In doing so, I explore the constituent elements of people's suffering, examining how participants justified, rationalized, or sought authentication from a doctor for their decision to die in light of their own belief systems and aesthetic preferences for a good death.

#### **KEYWORDS**

Assisted suicide; death and dying; decision-making; euthanasia; suffering; right-to-die

Medicalized deaths have become increasingly visible as a subject for media attention in recent decades. Discussions about the moral status of voluntary euthanasia, in particular, have been a prominent feature in the news media in many countries. At the time of writing (2016), legislation permitting some form of voluntary euthanasia or assisted suicide has been passed in the Netherlands, Belgium, Luxembourg, a number of US states, most recently California, and is currently being drafted in Canada. The practice is also lawful in Switzerland. In this article, I focus on one development which has escalated the debate in the United Kingdom and elsewhere in Europe over the past ten years: the possibility of travelling to Switzerland for an assisted suicide—so-called suicide tourism.

I aim to provide some insights into what the option of 'going to Switzerland' represents through an analysis of the experiences of people all actively making arrangements to undertake this journey. While I agree with Kaufman (2005:26) that "the problem of death," as it arises in the bureaucratized and rationalized health care systems of late industrialized societies, is far broader than the widely publicized quandaries of individual choice-making, it is also necessary to shine anthropological light on the "notable minority" (Chapple et al. 2006:708) whose choice to opt for an assisted suicide receives disproportionate media attention and evokes significant moral attention and public concern.

There is an emerging body of literature examining people's motivations for actively requesting an assisted suicide in jurisdictions where the practice is lawful (Dees et al. 2011; Norwood 2007; Pearlman et al. 2005; Pool 2000) and where this is not a legal option (Chapple et al. 2006; Lavery et al. 2001; Mak and Elwyn 2005). Overall, this literature suggests that requests for assisted suicide are rooted in suffering, which can have medical, psychological, social, and existential dimensions (Dees et al. 2011). These four domains bear similarity to the four dimensions of 'total pain' (physical, mental, social, and spiritual), a concept central to the development of the modern hospice movement (Saunders 2006). The literature suggests that while those who request an assisted suicide are suffering



from symptoms of illness or ageing, other factors influencing their quality of life can be important in motivating their desire to die (Hendry et al. 2013). These factors include dependency on others; hopelessness; loss of 'self,' meaning or dignity; loneliness or loss of social connectedness; and being tired of life (Hendry et al. 2013). Although the existing literature acknowledges the "profoundly personal perception" of suffering and the huge diversity of motivations (63 separate motivations counted in Dees et al. 2010:342), there is still a tendency to try to develop a typology of suffering and to quantify the incidence of each 'type' (Dees et al. 2011). This can feel reductive of real life experiences.

In this article I aim to interrogate people's 'profoundly personal perceptions' of suffering through an analysis of their accounts of their motivations for seeking out an assisted suicide in Switzerland, without attempting to compartmentalize or reduce their suffering to a 'type.' I aim to give a sense not just of why they wanted to die, but also why they wanted to die a particular kind of death. I also present an ethnographic account of a self-deliverance workshop teaching people practical techniques for taking their own life, which for some felt like the only alternative to 'going to Switzerland.' Each 'do-it-yourself' technique evokes a very different aesthetic to the professionalized assistance offered in Switzerland. Through my analysis of participants' accounts, I aim to contribute both to theoretical discussions about the nature of suffering and the meaning attributed to it in a secularized world, and to debates about the aesthetics of the 'good death.' While for some of my participants who had exhausted all other remedies for their suffering, 'going to Switzerland' was a last resort, for others the choice was about the aesthetics of how they wanted to die, by which I mean the attachment of values to the physical and practical experience of that event (Sharman 1997). With proposals to legalize assisted suicide being debated in the British and Scottish Parliaments in 2014 and 2015, as well as in other legislatures around the world, it is vitally important to gain insight into what this new mode of death means to those actively requesting it. The testimonies I present here indicate that suffering is specific to each individual and to the disparate contexts that make up people's biographies, posing a serious question for lawmakers around the world as they try to establish general rules and principles by which people would qualify for a 'right' to die.

#### **Background**

Voluntary euthanasia involves a deliberate act to end a person's life by another, at the request of the person killed (Lewis 2007:5). Where it is lawful, as in the Netherlands and Belgium, it must be undertaken by a doctor. 'Assisted suicide' denotes the act of providing the means for a person to end his or her own life. In other words, the lethal medication is self-administered rather than administered by a third party (Lewis 2007:5). At present, both voluntary euthanasia and assisted suicide are illegal in the United Kingdom.<sup>1</sup>

The arguments advanced for and against voluntary euthanasia and assisted suicide in the United Kingdom are broadly the same as in other medically advanced countries. Long-standing religious opposition stems from the principle of the sanctity of life—that only a divine being has the moral authority to end life through natural causes. Although proponents often characterize all opposition as being religiously motivated, many nonreligious people also oppose legalization, arguing that killing patients would result in an irreversible change in medical ethics and would endanger the doctor-patient relationship. They also argue that patients might feel obliged to request euthanasia to avoid being a burden to their family or society more generally. There are concerns too that there would be a 'slippery slope' toward assisting the deaths of people who are chronically ill; in the early stages of dementia2; and/or old and 'tired of life.' Proponents, on the other hand, see assisted suicide and voluntary euthanasia as part of a caring response to intractable suffering and as an aspect of the fundamental principle of self-determination (see House of Lords 2005a). Fundamentally, an ethics of autonomy is pitted against an ethics of care in a heated debate within medical, political, and religious circles in the United Kingdom and throughout the media.

The progressive mobilization of the right-to-die movement, beginning in the 1970s, has commonly been attributed to the post-World War II escalation in biomedical technologies and hospitalization at the end of life (McInerney 2000:141). Toward the latter half of the twentieth century, there were growing concerns that medical technology was being used inappropriately to prolong life but with poor quality (McInerney 2000:141). Historian Shai Lavi (2005:163), however, has presented an alternative view, arguing that demands for a 'right to die' are a product of a much broader Enlightenment desire for technical mastery over the world and a concomitant loss of 'art' in dying. The art of dying was very much shaped by religious belief in an afterlife and the idea that the deathbed scene could become a spectacle, witnessed by others, through which the most fundamental aspects of living would come to light (Lavi 2005:9-12).

In recent years, the United Kingdom's pro-right to die lobby has benefitted from sustained media interest in stories of Britons travelling to Switzerland to receive lawful assistance to die-so-called suicide tourism.<sup>3</sup> The vast majority of assisted suicides in Switzerland are arranged by privately run, non-profit-making organizations, rather than by health care providers (Ziegler and Bosshard 2007). The first (and best known) of the three organizations catering to foreign nationals is Dignitas, and the first recorded instance of a Briton travelling there to die was in 2003. Although Swiss law does not require that a person has a medical condition in order to be assisted to die, all three<sup>4</sup> organizations stipulate this as a precondition. For example, a person applying to Dignitas must be able to prove that they have a terminal illness; an unacceptably incapacitating disability; and/or unbearable and uncontrollable pain.

A number of documents are required for consideration by the organization, some of which can be difficult for people to source.<sup>5</sup> Applicants are advised that it can take several months from beginning the process to being offered a date for their assisted suicide or 'accompaniment' as it is called. The total cost is estimated to be approximately £8000 or US \$12,000. Once in Switzerland, a person must have two consultations with the Swiss physician, the second consultation taking place three days after the first, in order to ensure they have not changed their mind. While the physician is required to write the prescription, he or she is not present at the time of death. This is facilitated by a Dignitas volunteer and takes place at a house owned by the organization on an out-of-town industrial estate. Once a person swallows the lethal barbiturate, it takes between two and five minutes for them to lose consciousness and between 20 and 30 minutes to die (see FATE members' Guide to Dignitas; Dignitas website).

#### Methods

This article is based on interviews (conducted in 2007-2008) with seven individuals who had all applied to a Swiss right-to-die organization in order to be helped to end their own life, and participant observation at a do-it-yourself or 'self-deliverance' workshop in the United Kingdom where people learn techniques for taking their own life. Both strands of the research were carried out as part of a broader anthropological study of the UK right-to-die debate, the general aim of which was to discover how far this contentious and high-profile 'conflict of rights' represents a new way of anticipating and talking about death and dying in the United Kingdom (Richards 2015, 2016).

The seven interviewees were all recruited during ethnographic research conducted with a rightto-die organization based in Scotland (but with a UK-wide membership), called Friends at the End (FATE) (Richards 2012). FATE is the United Kingdom's main point of contact for all three Swiss right-to-die organizations offering assisted suicide to Britons. Since direct application to those organizations is possible, it may be that the people who contact FATE have more complex issues to resolve, such as lack of a terminal diagnosis. However, statistics acquired by the UK press (Campbell 2009) reveal that although the majority of the first 114 Britons to die with the help of Dignitas had either cancer (n = 36) or a progressive neurological disease (n = 57), others had chronic illnesses that were not life shortening, for example, rheumatoid arthritis or Crohn's disease. This is consistent with other studies (cf. Fischer et al. 2008) and suggests that the individuals who took part



in my study, whose medical conditions were, in the main, nonterminal, are not untypical of those being helped to die in Switzerland.

FATE 'befrienders' (their term) were responsible for assessing people's suitability for inclusion in the study in terms of their mental state; the sensitivities surrounding their case; the appropriateness of an interview; and whether they were likely to benefit from being interviewed, for example, by having an opportunity to air their views. In her study into the practice of euthanasia in the Netherlands, Norwood (2007:159) found that most people "do not make important (life and death) decisions without consideration of and in consultation with people they care about." For most of my interviewees, such consultations were not possible as they wanted to keep their plans a secret from family members. This was due to a fear of causing them distress; a fear of them intervening to prevent their departure; or a fear of criminally implicating them. It is possible that both FATE befrienders and I were the only avenues for 'euthanasia talk' (Norwood 2007) prior to their boarding a plane to Zurich or Bern. For example, one interviewee commented that our frank, in-depth discussions prior to her death enabled her to 'speak honestly,' something she was unable to do with any of her friends or relatives for fear of causing them distress.

The FATE befriender would initially approach prospective interviewees for consent to be contacted, after which I would provide them with detailed information about the study, verbally confirm their consent to be involved, and then arrange either a face-to-face or a phone interview. It is possible to surmise that the small number of interviewees recruited to the study was attributable both to the fact that people planning to end their life are likely to be too unwell to participate in an in-depth interview, and to the clandestine nature of making preparations to travel to Switzerland, given the uncertain legal situation at the time the research was conducted.<sup>6</sup> The sample is therefore a convenience, not a representative sample (Bryman 2008:183). For this reason, I could not aim for thematic saturation but rather aimed to contextualize each individual's beliefs and motivations in order to reflect theoretically on the aesthetics of assisted suicide and on the ways in which suffering is given meaning (or not) by the participants, and to conceptualize the right-to-die debate more generally.

Table 1 details some basic characteristics of the interviewees, along with their stated medical condition and method of interview. Anonymity was crucial, given the uncertain legal situation, <sup>6</sup> and many participants were reluctant to sign any documentation or to have their interviews digitally recorded for this reason. In such circumstances, hand-written notes were taken, which explains the lack of longer verbatim quotes from these participants. My participation in the 'self-deliverance'

Table 1. Participants'	Age, Gender,	and Medical	Condition(s);	Interview	and	Recording	Method;
Known Death by Ass	sted Suicide ir	Switzerland.					

Age	Range	52-93
Gender	Female	6
	Male	1
Medical condition(s)	cancer	2
	skin disease	1
	frailty	2
	dementia (suspected)	1
	multiple sclerosis	1
	spinal pain	1
	vertigo	2
	osteoarthritis	1
Interview	In person	5
	By phone	2
Repeat interviews/contact	One interview	2
	Repeat interviews/contact	5
Recording method	Digital recording device	2
-	Notes by hand	5
Had assisted suicide in Switzerland?	Yes	5
	No	1
	Unknown	1

workshop was agreed with the organizer, who sought consent from the other attendees prior to my observing and participating in the day's activities. I took notes throughout the workshop.

Before the workshop and before each interview, I stated clearly to participants that I did not personally hold a view on the morality of assisted suicide. I expressed sympathy with participants' desperate situations as they described them to me, but took care not to give the impression that I either supported or disapproved of their chosen course of action. I have disguised participants' identities to avoid recognition as much as possible, given the uniqueness of their situations.

An inductive and interpretative approach (Kleinman 1988) was taken to analyzing the interview and observational data. I did not assume that listening to and recording people's narratives gave me direct access to their experiences; rather they provided insights into how people tried to construe their life stories in a meaningful and coherent way (Good 1994:139). My intention was to ground my interpretations in a detailed knowledge of the UK right-to-die debate more generally, paying attention not just to the claims people were making, but also to their explanatory logic, the biographical context, and their cultural frames of reference. While the framing of this article is mine, and I have necessarily had to reduce what was told to me by selecting features from people's experience, I have tried to distil participants' reasoning in a way that both preserves their logic and connects their stories to one another.

#### A self-deliverance workshop

In December 2007, I found myself in a conference room in a cheerless hotel in central London. Around me sat 15 people of varying ages, although all appeared older than sixty. We had broken off into smaller groups and were undertaking a practical exercise. This involved a tank of helium, some metal clamps, some rubber 'polytubing,' and a large plastic bag. "These clips are so stiff. I suppose it's my arthritis," commented one woman who sat on the floor trying to assemble the apparatus. She then proceeded to put the large transparent plastic bag over her head: "I just want to see what it feels like." At the end of the plastic bag there was a tie, which she began to tighten. Three or four of us looked on. She suddenly appeared to panic and quickly removed the bag from her head. "I'm not sure I liked that. I felt smothered." In this particular simulated exercise, the aim is to attach the helium tank to the plastic hood via the polytubing. The 'stiff' clamps are required to make the connections airtight. For the purposes of the demonstration, our tank is empty and none of us is willing to keep the bag on our head for more than a few seconds. However, this simulation is intended to prepare participants for an imagined future time when they might actually choose to apply this method. At this (imagined) time, they would place the plastic hood over their head, pull the tie closed loosely around their neck, open the tank valve, lean back in their chair and let the odorless, tasteless helium gas pass into the hood, displacing the oxygen in their body as they breathed it in, causing them to asphyxiate within 15 minutes.

This workshop was about 'self-deliverance'8 or 'rational suicide.' It was organized by EXIT (Scotland), which runs a series of interactive workshops at venues across the United Kingdom every year. EXIT is part of a small but influential segment of the international right-to-die movement which supports a 'technological imperative': the harnessing of technology to enable lay persons to bring about their own death (Ogden 2001). Such workshops claim to offer people information rather than advice; to demonstrate recent developments in self-deliverance technologies; and to share findings regarding the application of those technologies. The workshops are therefore lawful because they do not encourage participants to commit suicide, but are unregulated.9 The validity of the techniques taught during the workshop was discussed in terms of likely success rate, accessibility, speed of death, and painlessness. The knowledge gained here was presented as an 'insurance policy' in case of future poor health.

The helium method is only one of a number of methods by which one can self-deliver. With each new technique simulated in our small workshop groups, people seemed to be imagining themselves performing the act in their final moments, trying each method on for size, checking if it fitted their

requirements and circumstances, even their personalities. In their own way, attendees were attempting to 'tame' death (Aries 1983) through harnessing technology to service their desire for control over it. The organizer placed great emphasis on the idea that choice of method is person-specific. There was a sense in which a person's final moments could say something about who they were, or rather, who they had been.

In early modern England, choice of method for suicide was indicative of a person's social status (MacDonald and Murphy 1993:185). For example, the conventions of honorable suicide dictated that death by pistol or sword was the preferable aesthetic for a 'gentleman.' This was because it was associated with courage and being resolute—a deed of calm reason rather than rash impulse. Men of lower class and women of all classes were more likely to drown, hang or poison themselves, given limited access to lethal weaponry (1993:248). Of all the ways to die, hanging was reputed to exert a particularly malignant influence and was considered contrary to the conventions of 'honorable' suicide, although for many it was the only means available to them. The idea that the way a person died reflected their moral substance or character was also evident in the ars moriendi or 'the art of dying' manuals produced in England in the Middle Ages, which instructed people in how to act on their deathbed. The implication was that the deathbed scene could become its own Judgement Day, with a person's 'goodness' being put to the test and his or her essential self being revealed and defined for all eternity (Lavi 2005:20).

I suggest that a preferred aesthetic for dying is determined by the value an individual or a cultural group attaches to the sensory experience of the 'event' of death. The anthropology of aesthetics has a long history of investigating indigenous aesthetic principles underlying appreciation of works of art (Coote and Shelton 1995:7). More broadly, however, aesthetic perception can be understood as the attachment of value to the sensory experience of objects or events (Sharman 1997:178). Individuals who are contemplating their own self-chosen death may imagine a certain manner of death, reflecting something of their character or the values they have subscribed to in life. Through the way they elect to take their own life, it is envisaged that the character of the life embodied can be preserved even if the body itself is voluntarily sacrificed. The ars moriendi similarly taught that the state of a person's character (or spiritual condition) was revealed in the critical last moments of life. For individuals contemplating 'rational' suicide, their vision of their own death is influenced by culturally determined notions of the good death (Aries 1983), as well as by how they want to be remembered, and how the way they die might influence this.

Not everybody who wants to end their life due to the effects of illness or ageing is prepared to learn or carry out one of the do-it-yourself methods taught in self-deliverance workshops. The seven participants in my study were all making plans to travel to Switzerland. When I asked them if they had ever considered self-deliverance, one revealed an unsuccessful attempt with prescription medication, another said she was stockpiling morphine but was concerned that her tolerance was too high to successfully overdose, and another had acquired a bottle of sodium pentobarbital (the drug prescribed in Switzerland) on the black market. However, participants expressed concerns about the efficacy of the method ("getting it right"); being interrupted; who would find the body; and having to "take full responsibility" for their actions without any emotional support. One woman said that only a lethal prescription from a doctor would make her death "civilized and certain"; another used the term "foolproof"; still another said that she wanted to "go with a bit of dignity."

These comments suggest that, for some, the method of suicide most in keeping with their own aesthetic preferences or views of a 'good death' was one which had both a guaranteed outcome and some social legitimacy because it involved a medical professional. As one woman said, "It is hard to die by your own hand; assisted suicide makes it easier." Without the option of going to Switzerland, some of my interviewees might have resorted to techniques of selfdeliverance. However, others might have demurred from this course of action for one or more of the reasons listed above, and would instead have had to find a way to continue living with their suffering.



#### Suicide and stigma

Throughout history and across cultures, suicide has been judged to be a quintessentially "bad death" (Van Gennep 1960:160-161), going against our fundamental human instinct towards self-preservation (Hobbes 1996[1651]). Particularly in Europe, acts of self-murder were variously regarded as affronts to God, natural law, or society, and the act has been criminalized until relatively recently (1961 in the United Kingdom) (Minois 1999). This history continues to influence public attitudes toward suicide today. In Christianity, it was St Augustine who first extended the sixth commandment "Thou shalt not kill" to include self-killing, which the historian Alvarez (1987:69) called an "afterthought" inspired by the suicide mania that was prevalent among early Christians keen to find eternal glory in the afterlife. Since that time, Christian doctrine has emphasized the 'sanctity of life' the principle that human life has intrinsic and not just instrumental value, because it is a divine gift.

Out of all the religious proscriptions against suicide, I focus on the Christian position because, of the seven people I interviewed, three were committed Christians. Of the others, two identified as atheists (of whom one was ethnically Jewish), one as agnostic, and another was a practicing Jew and attended synagogue weekly. Even amongst the non-Christian participants, there was a reluctance to accept that the outcome they were seeking would be judged to be 'suicide.' Jane, who had terminal cancer, said she was very much attracted to the idea of a medicalized procedure, because then it "wouldn't have to come in the same bracket as suicide." She said that there was something "seedy" about taking your own life at home, and expressed disappointment when she found out that Dignitas operated out of a residential apartment rather than a more medicalized 'clinic.' Christine, a 93-yearold Jewish woman, said she did not think that what she was doing constituted suicide, but accepted that "unfortunately, it is." She said she was "very frightened of it" but that she had still determined that "it is better to take that step once and then it is finished" rather than face a protracted decline.

Each of the Christian participants was wrestling with fears of God's judgment. For example, Sara's belief in her own goodness/godliness did not fit with a death by suicide. She had applied to Dignitas after a fall a few years earlier had left her with constant and excruciating spinal pain. Although she felt that using the services of an established organization like Dignitas would incur less wrath from God than "doing it myself," because it would entail a legitimation of her decision by a doctor, she still feared that she would go to hell for her action: "I find God very judgmental and censorious just now. I pray to Mary instead. . . . I'm sorry for my sins. I'm sorry for my pride or complacency, but I don't think I've lived a bad life. But can I say I have lived a good enough life?" Her Anglican priest's consolation that God would see her suffering and forgive her ("I desperately want him to forgive me") did not appear to relieve her inner torment.

For Morna, who had also applied for an assisted suicide, religious fears played a part, but this time they were the fears of her family. Morna's grown up children had intervened on numerous occasions to prevent her from travelling to Switzerland. As she explained to me, in addition to trying to talk her out of her decision by telling her how loved she was and how they would look after her as her disabilities progressed (she had multiple sclerosis), they had also raised the question of God's judgment:

My son says to me, "where does God come into all this mum?" And I say, "That's what I want, I want to go and be with God." And my son says: "If you think you're going to be with Dad, you might not end up where he is, but end up in the other place." I tell him, "well, I'll take my chance, I'll take my chance."

For the Christian participants, the perceived sinfulness of suicide played on their or their family's conscience and had to be reconciled in some way with their decision to seek an assisted suicide. Moral questions were expressed in religious terms through discussions of hell, sin, and forgiveness. Morna's comment to her son that she would "take her chance" of facing eternal damnation in hell, shows her ultimate resolve to escape her suffering in this world at the risk of unknown suffering in the next. So, while these participants were wrestling with religious prohibitions and notions of theodicy, they were also addressing questions of freedom, choice, and responsibility.

In the extended case study following, I explore in detail the moral deliberations articulated by a third Christian participant, Sheila. The reason for exploring Sheila's story in-depth is to give a sense of how the decision to opt for an assisted suicide is never solely attributable to people's underlying medical condition, but is bound up with their social relationships, their preferred aesthetic for dying, how they conceive of or value the 'good life,' and therefore what, for them, constitutes a 'good death.'

#### Sheila's conflict

I met Sheila, 58, a few months before her assisted suicide in Switzerland. She seemed to be a very private person, and she suggested that this resulted from feeling that she had been mistreated by people in the past. She had since become very careful about those in whom she placed her trust. She was estranged from her family after a childhood seemingly memorable only for its scenes of violence and victimization. She was divorced and had no children. Her desperate desire to be independent of her troubled family had inspired her to cultivate entrepreneurial skills which led her to set up her own very successful business working with an elite client group. Sheila spoke proudly of her strong work ethic, her business acumen, and her ability to overcome the hardships of her childhood. She told me: "Nothing is insurmountable if you have the will to overcome it," nothing that is "except for my health."

Eight years prior to our meeting, Sheila had developed a rare skin disorder for which there were no safe pain alleviating drugs and no known cure. Her disease was the one thing beyond her control to remedy. She would wake up every morning with her sheets covered in blood after a night of interminable scratching: "The constant irritation would drive anyone mad," she said. The open sores on her body would often become infected and several times she ended up in hospital covered from the neck down with bandages to prevent further scratching. The scars she showed me on her arms and legs spoke of the virulence of her disease. Her immunity to the most powerful steroids, coupled with her entrepreneurial attitude, led her to seek out various alternative remedies and new drug trials—"I didn't want to be beaten." When I met Sheila, she was participating in a drug trial which, while keeping her skin disease at bay, was damaging her body in other very serious ways. As a result of this, her doctor had insisted she come off the trial, and it was the anticipation of her skin disease returning which had caused her to apply to Dignitas: "I cannot bear the thought of going through the symptoms again."

When Sheila's illness became long-term, she felt she was abandoned by her upper-middle class social world. Her skin disease seemed to evoke a number of psychological issues from her past, which she believed she had overcome, and she said that she felt "dirty" and "contagious" again: "Nobody is interested and nobody understands what I have to live through," she said. Having lived with the disease for eight years, she was "not prepared to live with it anymore" and made the decision to travel to Switzerland for an assisted suicide. Only this option made her feel "optimistic" about the future: "If something has stopped me enjoying my life, then it is no life."

A strong believer in the Old Testament, Sheila said she thought of God as a father-figure and she prayed to him to respond to what was, in her view, a "hopeless" situation: "No one can have prayed for an answer as much as I have. He [God] could have sent me an answer. Now this [an assisted suicide] is the only option I feel I have left." She read and reread the Book of Job, the biblical story that most directly deals with the issue of theodicy. Sheila even saw her itchy, infected sores reflected in the "sore boils" which afflicted Job "from the sole of his foot unto his crown" (Job 2:7). However, unlike Job, she did not believe that her sores were a physical manifestation of her sins: she believed that she had led a virtuous life. While she worried that God would not forgive her for deliberately ending her life, she also expressed the view, like Sara, that "hell can be here on earth" as well. Although at times she felt that her decision was made more difficult *because* of her religious beliefs, she said that ultimately, if God did not agree with her decision, then he would have shown her "another way, opened another door for me." She eventually determined that she herself was responsible for finding a solution. This I identify as Sheila's existential dilemma. Applying Sartre's

(1996) existentialist philosophy, while she was prepared to accept her "radical freedom" in finding a solution and choosing death for herself, she was also "condemned to be free" because in making the hardest of all her choices, she had to sacrifice a part of her faith. She said: "Without Him [God] I would have to be more selfish. I would have to believe in me." Now, however, it was that selfishness, that desire to be relieved of her suffering in spite of her faith, that meant she was able to take her own life in Switzerland.

#### Remedies for suffering

When I asked Sheila if she expected to be eternally damned for taking her own life, she said that she no longer believed in a physical place called hell. The sociologist Tierney (1993:156) commented that, in late modernity, even though people may be willing to profess their faith in a Christian God, belief in heavenly immortality no longer convincingly guides human actions. Although the need for God remains strong because of our anxiety about our mortality, Tierney continued, the idea of a realm of immortality, access to which is determined by God, no longer offers us the comfort we desire. Instead, we find ourselves turning to convenience and technology in this life as a way of denying the body's limits (1993:156). Lavi (2005:169) too is convinced that calls for medical euthanasia are an extension of the modern desire for technical mastery over biological processes, a prioritization of technique over a more religiously inspired 'art' of dying. Certainly it was the convenience of a technologically assisted death that gave Sheila the comfort she sought, not the thought of a place in heaven if only she tolerated her suffering. However, it is my view that medically assisted suicide, just like techniques of self-deliverance, has its own 'art' or aesthetic value, and just like the ars moriendi of the middle ages, the chosen technique can in itself reveal something of the identity of the dying individual.

Religious interpretations of suicide have generally (although not uniformly) declined in the western world and so too have explanations of pain and suffering. In the Christian world, suffering had long been understood to have a purpose because it had the power to redeem sin and purify the soul (Lavi 2005:35). However, as the common interpretation of pain has become slowly de-Christianized in the United Kingdom and elsewhere since the nineteenth century, so it has been turned into a medical 'problem' instead. Pain and suffering, which persist despite medical interventions, whether at the end of life or in states of chronic illness, as in Sheila's case, tend to exacerbate calls for legalizing assisted suicide or euthanasia. Having tried to make sense of her pain over a number of years, with recourse to the story of Job amongst other coping strategies, Sheila was unable to find it redeeming. In fact, none of my participants, Christian or otherwise, was able to make sense of their suffering. This lack of meaning prompted them to make arrangements for an assisted suicide, a mode of death which, with its specific aesthetic of control, certainty and resolution, restored some meaning for them. As Lavi (2005:72) suggested, pain's annihilation through hastened death has in the twenty-first century become medicine's own theodicy.

As anthropologists have highlighted, individual suffering is influenced by a person's social conditions, with relationships and interactions often taking a central part in the experience (Kleinman 1988). In Sheila's view, the fact that she did not have a family and had been abandoned by the majority of her friends and colleagues, who "didn't want to hear about my illness anymore," contributed to her decision to seek an assisted suicide. If she had had family responsibilities, she told me, she might have made a different decision. Her suffering was also compounded by memories of being victimized as a child and feeling helpless in countering that victimization; these resurfaced as a result of her vulnerability in the face of 'insurmountable' illness. So while suffering is uniquely experienced at an individual level, it can be caused or compounded by social factors, specifically a lack of social support. Research suggests that Swiss nationals who were helped to die by a right-todie organization were more likely than the general population to be socially isolated (living alone, being divorced, not having children) (Steck et al. 2014). However, these results are equivocal and permit the alternative: that social responsibilities may prevent a person from bringing an end to their



suffering as they otherwise might wish. In other words, a person's preferred dying aesthetic is likely to be influenced, one way or another, by their social relations.

The phenomenological and intersubjective dimension to suffering suggests that it can be understood only in terms of how it is experienced by the person who is actually suffering (Cassell 1982). This presents a problem for lawmakers who have to provide objective legal criteria defining the basis upon which a person might be assisted to die. In the Netherlands, for example, medically practiced euthanasia is considered lawful provided that doctors comply with various 'due care' criteria, one of which is that the patient's suffering is categorized as 'unbearable.' Only suffering which is predominantly caused by a medically recognized disease or disorder can qualify under the 'due care' criteria. For some legal commentators (Ost and Mullock 2011:170), allowing assisted suicide for those whose suffering stems from a medical condition but not for those whose suffering stems from social factors is inconsistent with both an autonomy-based position and with an approach based on compassion.

It is precisely the multidimensionality of suffering that presents us with a serious analytical problem when trying to unify or classify people's experiences of it. Further still, burdening doctors with the power or duty to judge which 'types' of suffering might qualify a person for an assisted suicide presents additional problems. During a 2006 debate on proposed legislation brought before the British Parliament, it was suggested that as practiced in the Netherlands, a patient's claim to be 'suffering unbearably' would have to be confirmed as 'reasonable' by an attending physician (House of Lords 2005a:58-60). In other words, a person's own subjective assessment of their suffering and persistent desire to die should not be sufficient reason in itself. However, as a Swiss physician giving evidence to the British Parliamentary Committee commented, "physicians have no particular expertise for unbearable suffering" (House of Lords 2005b:541). This is the crux when it comes to medicalized assistance with suicide. Given the interpersonal dimensions of suffering which a case like Sheila's reveals, can it be argued that doctors have the necessary expertise in recognizing or diagnosing suffering, or that the response to such accounts of suffering should be medicalized? In the Netherlands, where both voluntary euthanasia and assisted suicide are lawful, the assessment of whether or not the patient's suffering is 'unbearable' is seen as the most challenging aspect of the legislation; while a physician might acknowledge that a patient experiences their suffering as 'unbearable,' he or she may not be convinced that this is objectively so (Buiting et al. 2008). There is also little support amongst Dutch physicians for extending the definition of 'unbearable suffering' to people experiencing non-medical (social) suffering (Rietjens et al. 2009). While some legal commentators have tried to resolve these dilemmas by advocating for a de-medicalized model of assistance (Ost 2010:537), it seems likely that any model of assisted suicide will retain a significant medicalized aspect so long as suffering associated with a medical condition is perceived as a more legitimate reason for wanting to end one's life than any other reason (Ost 2010).

Some of the participants in this study agreed with the sentiment of the Swiss doctor quoted, and questioned the need to involve a physician in their decision to die. Gwen, for example, said that she did not want a doctor to have "power over my life in that way." For that reason, the Swiss model of lay assistance appealed to her aesthetic preference because the Dignitas apartment, where the death occurs, is markedly nonmedical in its aesthetic. Phillip, a Jewish émigré from Poland, told me that he resented "being dealt with as a medical object": "Doctors take a medical oath by which they agree to use their knowledge and experience to the best advantage of the patient. It is for the patient to decide what that best advantage is." Like Gwen, Phillip would have preferred not to have to undergo medical consultations designed to assess and verify the 'reasonableness' of his suffering: "The very last thing I want is to be in the hands of others."

Like Sheila, Phillip expressed a broadly existentialist view on the human condition (cf. Sartre 1996): that each individual has the ability to choose freely his or her response to a given situation, and is responsible for that choice. Although Phillip was an acknowledged atheist and Sheila a devout Christian, both were willing to challenge the authority (of God or a doctor) which they felt was restricting their choices. Phillip resisted medical validation of the 'reasonableness' of his suffering. He was not seeking authentication from a doctor for his decision to end his own life. The reason Phillip and Gwen chose to 'go to Switzerland' rather than self-deliver in the United Kingdom was the certainty guaranteed them by prescribed barbiturates, and a desire to (legally and emotionally) protect their loved ones. His aesthetic preference for dying was for it to be at a time of his own choosing (before his dementia progressed any further) and with a guaranteed outcome. He was not looking for a doctor to authenticate his decision or share in the responsibility of taking his own life. What he wanted was for his death to be orderly and controlled and a doctor's lethal prescription would facilitate this.

Other people in this study clearly sought acknowledgment from their physician for their suffering. Sara, for example, explained that while her doctor had refused to write her the short medical report required by Dignitas, 10 he also denied her any 'basic compassion': "They have never held my hand and said 'sorry things are like this' ... They don't like people who are chronically sick because they are persistent and can never be cured." As Cassell (1982:641) argued, suffering can occur when physicians do not validate a patient's pain. For Sara, the ultimate validation of her pain would have been for a doctor to consent to assist in her suicide. A prescription from a Swiss doctor would mean that she would not have to take 'full responsibility' herself for her actions. For Cassell, suffering is very much part of the doctor's remit because practicing medicine is (or should be) about treating the whole person. Dividing the human condition into what is medical and what is nonmedical is, he argued, "misleading, distorting ... and anachronistic" (Cassell 1982:640). Certainly doctors are trusted members of British society (Ipsos Mori 2013) and their professional identity is suffused with a "transcendent value" (Friedson 2004:122) that people want conferred upon their own death decisions. Although suffering is multilayered and socially situated, the privileged position of doctors within our society, and their power as prescribers, means that they are called upon to respond to the desperate requests of those who want help to die.

#### Conclusion

The participants in this study were all trying to transcend their current or future suffering by opting for an assisted suicide in Switzerland, a death which would be guaranteed and painless, and which, reportedly, would give the appearance of going to sleep and thus of being 'natural.' This idealized mode of death matched these individuals' aesthetic preferences for a good death, and was considered preferable to the many self-deliverance techniques taught in workshops like the one described in this article. Assisted suicide as a mode or 'technique' of death was also perceived to fit with the person's character and to say something about who they were, or who they had been. When other remedies for suffering were not forthcoming, such as prayers not being answered, or a doctor not showing sufficient sympathy, an assisted suicide was envisaged as an answer.

For some of my participants, the involvement of a physician in their suicide would mean that the responsibility for making the decision to die would be shared, making it feel less like a suicide, which, as participants confirmed, continues to be subject to both religious sanctions and social stigma. For these participants, medicalized assistance and the legitimacy it conferred on their decision to die fitted their preferred aesthetic. For other participants, it was solely the physician's power as prescriber that was solicited. They rejected the idea that their decision needed to be validated or declared as 'reasonable' by a medical professional. This I identify as an existentialist view: the belief that each individual is faced with freedom of choice and is responsible for their own death decision. All participants in this study had ultimately come to the conclusion that their current existence was no longer consistent with their notion of a 'good life'; as Sheila said: "If something has stopped me enjoying my life, then it is no life." With the loss of a good life, death became a replacement 'good' which was strived for. An assisted suicide in Switzerland offered a particular dying aesthetic that fitted with participants' notions of a good death, involving certainty in timing and outcome, and control. Five of the seven participants in this study are known to have had an assisted suicide in Switzerland.

This study confirms that experiences of illness are always influenced by a person's social conditions. This was highlighted in the case of Sheila, whose desire to die was only partly attributable to her underlying medical condition but also undoubtedly influenced by her relationships, past and present. This finding is confirmed by other studies examining the motivations of people requesting an assisted suicide (Dees et al. 2011; Hendry et al. 2013). A primary question in the debate about whether assisted suicide should be legalized in the United Kingdom and elsewhere is where the limits of medicine lie in terms of the medical profession's responsibility to relieve suffering, given its phenomenological and intersubjective dimensions. Medical professionals have the power to facilitate certain modes of death and to legitimate suicide in certain circumstances. As Lavi (2006:57-61) suggested, the technological imperative to relieve 'hopeless' suffering means that medical assistance in suicide is increasingly viewed as a legitimate 'treatment.' UK lawmakers have so far proved reluctant to extend medical power over death by voting against proposed legislation. 11 As the individual cases discussed in this article show, requiring doctors to adjudicate on a person's level of suffering and to facilitate their suicide is problematic as soon as one becomes aware that suffering is rarely solely somatic but, rather, is bound up with people's biographies, social worlds, and existential dilemmas. None of these is static.

#### **Notes**

- 1 Voluntary euthanasia is prosecuted as either murder or manslaughter, while assisted suicide is prosecuted under the Suicide Act (1961).
- 2. The suicide in 2015 of a Cornell University Psychology Professor, Sandra Bem, who chose to end her own life due to the effects of Alzheimer's disease, received national media coverage in the United States, and was the subject of a special issue of the journal Feminism & Psychology (Kitzinger 2015).
- 3. Article 115 of the Swiss Penal Code considers assisting suicide a crime *only* if motivated by 'selfish' reasons.
- 4. Dignitas, in Zurich; EX International, in Bern; and Lifecircle, near Basel.
- 5. Dignitas requires a personal letter explaining your desire to die; a biographical sketch of your family circumstances; up-to-date medical reports; a passport; a birth certificate; a sworn affidavit as proof of residence; and proof of marriage/divorce/celibacy or the death of a spouse (see "Guide to Dignitas" printed by Friends at the End).
- 6. My research was conducted prior to the House of Lords ruling on the judicial review brought by Debbie Purdy which required the UK's Director of Public Prosecutions to publish a policy document specifying the reasons why a person might be prosecuted for helping another to die (R (on the application of Purdy) v Director of Public Prosecutions [2009] UKHL 45; Crown Prosecution Service, Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide (2010). See https://www.cps.gov.uk/publications/prosecution/assisted\_sui cide\_policy.html). Prior to the publication of this policy there was widespread concern amongst those wanting help to end their life in Switzerland that anyone who accompanied them, or even knew about their intentions in advance, was liable to be investigated by the police.
- 7. Given such sensitivities, all names ascribed to participants are pseudonyms.
- 8. To my knowledge, the term was first used in print in the UK's Voluntary Euthanasia Society's self-deliverance guide (1981).
- 9. In Attorney-General v Able [1984] it was held that members of the Voluntary Euthanasia Society who sold the self-deliverance guide (1981) had not committed an offence under the Suicide Act 1961.
- 10. In 2013 the UK's medical governing body, the General Medical Council, produced guidance authorizing doctors to consent to patients' requests for medical reports for the purposes of applying to Swiss right-to-die organizations (see http://www.gmc-uk.org/DC4317\_Guidance\_for\_FTP\_decision\_makers\_on\_assisting\_sui cide\_51026940.pdf (point 22)). However, at the time this research was undertaken, the legal position for doctors was less clear and many were reluctant to consent to patient's requests.
- 11. Most recently, the Assisted Dying (No 2) Bill 2015-2016 did not pass its second reading debate in the House of Commons in September 2015 (with 118 MPs voting for it to proceed and 330 against). See: http://services. parliament.uk/bills/2015-16/assisteddyingno2.html.

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