

## Article

# The Socio-Political Debate of Dying Today in the United Kingdom and New Zealand: ‘Letting Go’ of the Biomedical Model of Care in Order to Develop a Contemporary *Ars Moriendi*

Rhona Winnington <sup>1,\*</sup> , Eleanor Holroyd <sup>2</sup> and Shelaine Zambas <sup>2</sup> 

<sup>1</sup> School of Nursing & Midwifery, Faculty of Health & Human Sciences, University of Plymouth, Plymouth, Devon PL4 8AA, UK

<sup>2</sup> School of Clinical Sciences, Auckland University of Technology, Auckland 1142, New Zealand; Eleanor.holroyd@aut.ac.nz (E.H.); Shelaine.zambas@aut.ac.nz (S.Z.)

\* Correspondence: Rhona.winnington@plymouth.ac.uk

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**Abstract:** Death is a reality of life. Despite this inevitability, death today remains unwelcome and has been sequestered into the enclaves of medical practice as a means of quelling the rising tide of fear it provokes. Medical practice currently maintains power over the dying individual, actualised through the selective collaboration between medicine and law as a means of subverting the individual who attempts to disrupt the contemporary accepted norms of dying. There is, however, a shift on the horizon as to whether we can make the notion of a true choice become a reality in New Zealand. This serves to offer a compelling movement towards individuals seeking control of their dying trajectory to actualise the notion of individual choice. With this shifting landscape there is an opportunity to be grasped to change how we manage our dying trajectory away from the biomedical patterns of behaviour when dying, in order to balance life decisions. To achieve this prospect, we need to engage with a framework upon which to pin the changes. This paper offers a re-framing and re-presenting approach, using illustrative examples that draw upon British and New Zealand literature, together with over 50 years of professional nursing, and the *Ars Moriendi* to reflect upon the self-centricity of the contemporary Western individual to access a ‘good death’ of choice.

**Keywords:** end-of-life; palliative care; patient choice; death; dying; right-to-die; *Ars Moriendi*; medical power; euthanasia; assisted dying

## 1. Introduction

Death is all around us. It pervades our daily existence, yet it is simultaneously invisible. It is the absolute consequence of living. Death is a known inevitability, yet it remains an unknown entity; it cannot be avoided in the long term, it will not disappear, and it will happen to every living, breathing creature, but is ‘swept under the carpet’. Death will come to us all, it is immutable, with only the questions of when, how and where to be determined. However, through the contemporary self-centric need for control over the minutiae of life and the pursuance of a ‘good death’, the when, how and where of death have become subject to increasing socio-political and media attention [1].<sup>1</sup> This is particularly prominent in the United Kingdom (UK) and New Zealand (NZ) where the literature and clinical experience for this paper was situated.

<sup>1</sup> A ‘good death’ is suggested to be one that is pain free, dignified, and one in which active resuscitation never occurs [2].

The construction of a 'good death' has transcended the religious prescription of how dying occurs, with the contemporary notion of a medicalised death now meeting this criterion across many Western countries. This move has witnessed the religious framework of the *Ars Moriendi* as being no longer relevant to the contemporary death, as medicine is portrayed as being able to meet the needs of the dying patient today.<sup>2</sup> This is evident in the construction of specialist medical practices to care for the dying, under the global umbrella of palliation and the subsequent development of specific medical models of care to provide symptom relief for the dying individual.<sup>3</sup> This shift from religious structures as the overseers of death towards the medical practitioner, demonstrates how the socially constructed nature of the clinical institution, and the reliance upon such practitioners to fix us when unwell, opens the pathway for medicine to dominate other fields of natural living. This, then, underpins the clinician's ability to procure their position as expert over the human body and, as such, ensures the domination continues at our point of crisis or weakness. Doctors have become authorities in the subjugation of human life and death, and the body and the self, through the clinical institution being perceived as a trusted modality of power. This is particularly visible as fewer and fewer individuals identify as having any religious affiliation in both the UK [3] and NZ [4]. This trend is paralleled with a shift from dying in the community towards the increasingly impersonal, sterile setting of the medical institution. This shift has not occurred merely of free will but has transpired through the emerging and influential powers procured by medical professionals, and actualised through the 'medical gaze', together with the challenge of defeating mortality.

The medical gaze is a phrase coined by Michel Foucault [5] to signify the dehumanising aspect of medicine, whereby the human body is separated from the self-identity of the individual. In this stance, the physicality of the body is monitored but not viewed as being part of the whole individual, but rather as independent flesh to be prodded and observed. Through using the medical gaze as informing the analytical frame, this concept infers the notion of power within the dictat of medical practice, the presence of bio-power, and an authority possessed over the individual human body.

In terms of managing large groups of people, Foucault [6] suggested that bio-power is an exercise of power/knowledge (whereby, in this instance, the medical profession has control over the body, which then becomes the site of bio-power) and can be perceived as "an explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations" [7] (p. 140). This concept fits within Foucault's larger product of controlling bodies of population through different forms of surveillance and monitoring, which aligns with what occurs in the hospital setting. The idea, therefore, that the body is separable from the whole individual becomes problematic when the reality is that the human body and self-identity are complexly inter-related and, as such, require a more holistic approach to care [8]. Yet, the cartesian duality of the separation of the human body from the self remains a constant in many practices through the medicalisation of normative human behaviours. Moreover, this power can be further demonstrated in the belief that technological advances, for example in cardio-pulmonary resuscitation and defibrillation, or the life-support machinery in intensive therapy units, draw the patient into becoming a faithful follower of these interventions. This, in turn, renders some patients as impotent in the negotiations of choice, as technology can supersede the cultural and humanistic approaches to care [9]. Such technology can provide comfort to some individuals through the attributes of fact and objectivity [9]; however, these inventions are not necessarily driven by a patient's request [10] and, as such, oppose the notion that dying is a natural life event [11]. However, in its guidance towards how the contemporary death may now appear, medicine overlooks the role of individual subjectivity and the preference for specific experiences at this life point. This is highlighted in the legal cases where individuals no longer wish to endure the suffering associated with incurable

<sup>2</sup> *Ars Moriendi*, translates from Latin as the 'art of dying' and refers to a literary narrative of the same name developed at the beginning of the fifteenth century.

<sup>3</sup> Medical models of care refer to the Liverpool Care Pathway or palliative sedation therapy.

or degenerative conditions and seek an end to the prolongation of both living and dying, through pursuing the right to choice and death when their suffering becomes intolerable.

The right to choice and right-to-die discourses dominate contemporary social mediums of communication and the socio-political landscape within Western cultures (and the UK and NZ specifically), but they remain elusive in reality, despite individual choice being a promoted ideal within healthcare [12]. Medicine is characterised as a curative field of practice that must contend with the inevitability of death, as avoiding such clearly contributes to the prolongation of living and dying. That clinicians may not be able to meet the needs of the dying, or those experiencing intolerable suffering, produces a reflexive abhorrence in that their expertise as gatekeepers of the dying is insufficient to quell the rising storm of those seeking control as individuals move towards death through methods that do not align with traditional medical care.

It is, therefore, this contemporary desire for control of the self at end-of-life that is proving problematic within the context of the medical narrative of care. To consider death as preferable to that of life produces a subtext of “otherness” for the individual involved.<sup>4</sup> It locates the self-determined individual outside the boundaries of the contemporary medicalised ‘good death’. To be other, however, does not quell those seeking the right to choice and the right-to-die, as such individuals remain resolute to their belief that control of the self should be attainable in death as it is in many other spheres of life, and that the right to choose one’s dying trajectory, whether medicalised or not, should not be contained and constrained by the powerful expert [1], but be attained in a similar manner to lives led, through the actualisation of the perceived freedom to make choices.

## 2. A Professional Perspective

As registered nurses with over 50 years of practice between us, and backgrounds across medical anthropology and sociology, as well as clinical experience, death in all forms has been encountered, from murder, suicide and accidents, to those from progressive and incurable illness, in both the UK and NZ. They are all different except for the inevitable ending of existence as we currently understand it. One author continues to work in specialist palliative care in New Zealand and remains fully immersed in the day-to-day practices within the organisation and beyond. Such professional experiences are, therefore, relevant to this debate, and are utilised through the engendered practice of reflexivity actualised over the many years of nursing practice and academic engagement. The use of such experience, therefore, to allow an engagement relative to the encounters experienced, brings a voice to the need to move forward in how we engage with the inevitability of death and the construct in which we currently die.

## 3. Medical Models of Care

Medicine, in having produced a construct supported by advances in technology to save lives, together with a narrative of technopoly that supports this notion [9] have created a powerful dynamic of authority over the human body. In doing this, medicine and technology have simultaneously developed specific medical models of care to provide symptom relief for the dying individual. While outside the scope of this paper, it is worth noting that palliative medicine, as a specialist field of practice, acknowledges that the patient is the best situated person to decide whether care approaches offer adequate relief from their suffering, yet it is medical practitioners who take decisions regarding offering certain palliative models of care [15,16]. This situation presents an uncertain picture of how individuals can invoke their right to participation and choice in care decisions, when there is clear potential that such decisions may be overruled through the application of expert knowledge to the given situation. Such decisions can be reflected in the use of specialist models of care at end-of-life;

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<sup>4</sup> ‘Other’ or ‘otherness’ refers to the social identities of those individuals who sit outside the cultural boundaries of what is perceived as being ‘normal’ practices [13,14].

for example, The Liverpool Care Pathway (LCP) and ‘palliative sedation therapy’ (PST), sometimes known as ‘continuous deep sedation’.<sup>5,6</sup>

The contemporary models of care highlighted have become fields of highly focused academic interest with a proliferation of primary quantitative publications, particularly in medical journals; however, there is considerably less scholarship investigating these therapies from a patient or family caregiver perspective. Despite the literature appealing to clinicians that PST is a last resort in caring for the dying [19–21], and that informed consent be essential when applying this therapy, the Royal Dutch Medical Association [22] suggests that this may not always occur in practice. As such, this has the potential to compromise the reality of individual choice being patient driven [11].

#### 4. Patient Choice

Choice, in a simplistic definition, refers to the “the power, right or liberty to choose” [23], referring to mental decisions or judgements resulting from the contemplation, comparison and deliberations of options available at any particular moment in time. However, these options may differ depending upon individual needs, social positioning and ability to exert agency in making such decisions. Such one-dimensional and unsophisticated suppositions around choice can demonstrate a naivety towards what can often be deeply complex situations from which decisions must be made.

Choice, however, can also be understood through how “*liberal subjects* constitute themselves through choice-making, where freedom is the necessary first premise of an historical ontology of ourselves” [24] (p. 392). In other words, choice is a means through which we both constitute and govern ourselves in the routine of daily life and which, therefore, will influence our decision making regarding healthcare and ultimately the dying process. Yet, choice is not necessarily this simplistic, as the choices we make through the consumption of goods and services are not made through free will alone, but become obligations through the notion that we are free in the first instance to make such choices [24]. However, we must recognise that our choices may impinge on others or are constrained by what is available and our ability to have the freedom to make such decisions. Moreover, it is possible that not all individuals act out of a premise of freedom, but that some will act out of necessity, or perhaps even ignorance and, as such, choice may not be the empowering tool we presume, but more of an encumbrance. Thus, our choices define the self we become and the life we lead and, as such, we become the sum of the choices made over a lifetime, ending with our choice of dying for those interested in the determinism of the self at this life point [1]. The naivety surrounding the notion of choice, however, becomes apparent in the context of sociological literature which, through a deeper exploration of the subject matter, problematises choice through the potential constraints of the socio-political landscape in contemporary Western cultures.

Individual choice decisions, however, will not be purely focused upon the physical dimension of their situation, but will simultaneously remain relevant to the lives already lived. It has been suggested that the next generation to die (specifically, the white European baby-boomers) will change what is currently occurring, namely the professionalisation of dying by medical practitioners [25]. The baby-boomers have experienced life through the lens of individualism and perceived freedom of choice [25]; but this could prove problematic as these individuals do not consider personal choice as being ‘otherness’.<sup>7</sup> The potential shift in care choices and directives by the baby-boomers allows for the prospect of the renegotiation of power relations between clinicians and dying individuals, but this has yet to come to fruition. This prospective revolution in dying appears to remain an insurmountable challenge when considered in relation to the power amassed by medicine, often supported through

<sup>5</sup> The Liverpool Care Pathway (LCP) is a model of care “for the dying patient” and “is a programme of integrated care that is used at the bedside in the last hours and days of life” [17].

<sup>6</sup> Palliative sedation therapy (PST) is a clinical practice aimed specifically at relieving refractory symptoms in patients at end-of-life that cannot be managed in any other format [18].

<sup>7</sup> Baby-boomers refers to those individuals born between 1946 and 1964.

legal practices and, as such, the individualism of the right-to-die voice becomes vacuous in the presence of constraining structures of medical power, demonstrating the potential weakness in individual agency in such circumstances.

In 2000, the *British Medical Journal* called to “... break the taboo and to take back control of an area [death] which has been medicalised, professionalised, and sanitised to such an extent that it is now alien to most people’s daily lives ...” [26] (p. 1). Currently, however, although little appears to have changed in clinical practice overall, there are some chinks appearing in the armour of medicine in the UK. More specifically it appears that when clinicians experience the reality of patient suffering from a personal perspective, as opposed to biomedical subjectivity, they are opening their minds to the possibility that for some patients the suffering is unbearable and the provision of palliative care, irrespective of how good it is perceived to be, remains insufficient to meet their needs [27,28]. Interestingly, David Nicholl, a British general practitioner, having experienced a friend opt for active euthanasia, cites that “... having a sense of control over how they depart this life is crucial to a good death. What right do those who oppose this as a ‘slippery slope’ have to impose their views on others?” [27] (p. 2); and Emma Young, a British emergency department consultant, encountering the barriers that those outside of medicine often experience when, in accompanying her mother to Dignitas, she “... resented having to consult with the General Medical Council and the Medical Protection Society about whether I could be at my mum’s death bed”.<sup>8</sup>

These quotes offer a powerful insight into the possibilities of change being made; however, it does appear to be at the cost of encountering personal experience as opposed to active engagement with a mutually constituted relationship of decision making with, and not for, a patient. Thus, the reality of personal freedom to choose is not as clear cut as we would like to think, as at present it remains constrained by the oppositional subjectivity of the involved participants [1].

## 5. How Do We Embrace this Opportunity to Transition from the Medicalised Death to One of Choice?

In order to move forward, we have to look retrospectively at previous practices and reimagine them to meet the needs of the contemporary self-centric individual. Moreover, rather than reinventing the wheel, the essence of need is to meet the needs and wishes of the individual at that end-of-life point. To change the landscape of dying perhaps we must, therefore, give due consideration to how the now disused *Ars Moriendi*, or art of dying, may look today.

The *Ars Moriendi* was an interpretation of religious guidance in how to die well, and is a transformative piece of literature that has remained relevant for many centuries. Although subjective, the need to attain a ‘good death’ was of importance then and remains prominent within contemporary discourses, such as in the UK and NZ today. It may now, therefore, be more profitable to revisit the art of dying through a contemporary lens, as there are no obvious reasons why the art of dying concept cannot be sufficiently malleable to meet the needs of twenty-first century living and, as such, moulded to incorporate the notion of individual choice—a key component in the contemporary debate over our demise [1]. In considering a new approach to an old narrative, the new *Ars Moriendi* may provide the opportunity to actualise the right to choice at end-of-life through Western societies accepting the naturalness of dying and implementing the ‘letting go’ discourse [29]. The idea that we can re-utilise a well-used historical narrative to develop a discourse of individual choice at end-of-life, however, is not as straight-forward as may be indicated. Medicine has developed such a far-reaching presence in overseeing the process of dying it continues to prove highly influential in retaining control of this life event at present [1].

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<sup>8</sup> Dignitas is a house on the outskirts of Zurich, Switzerland, where active euthanasia is a legal option.



## 6. The ‘Letting Go’ Discourse

The death-denying culture of contemporary Western societies remains tangible, as dying has moved from being visible and artful towards invisibility, existing at the edges of our consciousness [30]. The routine “mechanising and protocolising” [31] (p. 3) of many aspects of care renders dying less of an art form but rather a set of instructions and tick boxes for completion by healthcare staff [32], with this contemporary cultural response to death producing not only death-denying societies, but allowing the creation of narratives enhancing its mystery and terror [30]. The propensity to engage with the prolongation of life and death discourses has done little other than encourage engagement with the medical narrative of having to always fight death. Yet, as the life continuum is finite—remembering that we are ‘being-toward-death’ from the moment of birth [33]—to engage with the now well known ‘letting go’ discourse may prove beneficial [29]. Atul Gawande, an American surgeon, has embraced the finality of life, albeit from a positivist surgical perspective where there is always something else that can be done to prevent death, and narrates the ‘letting go’ narrative as a means of engaging positively with death.

To let go of a loved one is often to admit defeat in the face of death and is despised within contemporary Western culture and, as such, “if you don’t give up, if you fight, if you search hard enough, if the doctor is good enough, if the hospital is the best, if you are willing to spend enough—there is always something that can be done” [29] (p. 3). Reality, however, is that death will come eventually, it cannot yet be beaten, and as a collection of Western societies we need to engage with this fact. Yet, this is not a simple exercise to achieve. We are fed information, often through our consumption of media messages and the unstoppable babble of social media feeds that we are invincible and that we can overcome a multitude of diseases, thus, suggesting that the status of achieving longevity outplays the idea that to die well, at home, or in control, is no longer an essential element of the argument to choice.

Status holds priority for many individuals [34], even if such status is achieved through prolonging both life and death. The notion that status can be accorded with longevity even if individual suffering occurs appears a dubious position of prestige, yet is notable in the context of preserving life through equating endurance with the sanctity of life.<sup>9</sup> This narrative leads to the reinstatement of the sanctity of life argument within the socio-political debate in light of medicine’s ability to keep the human body alive, irrespective of the consequences to the individual. Social status equates with the subjectivity of the individual and must, therefore, always be considered within the context of the subjective, as this differs between individuals and between doctors and patients [1]. This suggests, however, that social status has been accorded to the prolongation of life through consensual acceptance of, and engagement with, the “expensive, [and] unlimited state of the art medicine” [36] (p. 3) available to keep individuals alive.

Professor Sheila Payne, President of the European Association for Palliative Care suggests that a “new social status [has developed as] more people live longer with advanced disease that will or may ultimately cause their death” as “the pattern of dying therefore is more likely to be prolonged, with bouts of illness . . . which may mean the spectre of death becomes closer” [36] (pp. 6–7).

As such, the individual’s increasing engagement with the medical profession throughout the lifespan produces a narrative through which disengagement with the clinician at the end-of-life becomes abhorrent, thus opening the pathway for the subordinated medicalised death. Yet, Gawande [29] suggests that the disengagement with the medicalisation of dying is an important factor in encouraging engagement with the naturalness of this life event. The recent discussions around the use of Advanced Care Plans (ACPs) was a small step towards our ability to let go, although these remain

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<sup>9</sup> The sanctity of life refers to the notion that human life is precious and holds a value that should not be violated [35].

firmly located within the biomedical context with no automatic right to choice available [37,38].<sup>10</sup> However, the notion of letting go should not merely be about declining medical interventions, but should be about the encouragement of active engagement with individuals' preferences at end-of-life, whatever these may be; this can be seen in an address by Pope Francis in that " ... even if we know that we cannot always guarantee healing or a cure, we can and must always care for the living ... but also without futilely resisting their death" [40] (p. 7).

There is some comfort to be had in that some individual choices have been acknowledged and engaged with in the UK (but not in NZ) at this time, with Debbie Purdy, Simon Fitzmaurice and Miss B being examples of this. More specifically Fitzmaurice, an award-winning writer and film director who developed motor neurone disease (MND), challenged clinical decision making in 2013 after experiencing "respiratory failure, caused by his Motor Neurone Diseases, (which) resulted in his being ventilated in hospital. A doctor he had never met came to his Cork hospital bedside and in front of his wife and mother, told him 'It's time to make the hard choice' i.e., to die. He was told he could not go home on a ventilator essentially because medical policy in Ireland was not to ventilate patients with MND. Fitzmaurice fought, won and went home to his wife and three children, with the aid of a ventilator" [41] (p. 577).<sup>11</sup>

Debbie Purdy had multiple sclerosis and in 2009 was given permission to travel with her partner to Dignitas in Switzerland without fear of her partner being prosecuted. This was a landmark case in the UK at the time. In 2002 Miss B, a former social care professional suffered a catastrophic rupture to a blood vessel in her neck at the age of 43, rendering her tetraplegic and unable to breath unaided. Miss B, who had been kept alive for 11 months on a ventilator, made an application to have her enforced treatment stopped and, thus, die [42]. Being considered of sound mind, Miss B made a legal bid to be removed from the ventilator, but medical practitioners refused her request; they found it difficult to comprehend that such a young woman would give up on life. Clinicians pursued this patient through the courts while she remained hospitalised to convince her to engage with medical solutions for her condition, despite her protestations of suffering and poor life quality. Moreover, they refused her request because she had not yet "tried special rehabilitation to improve her condition" [43] (p. 565). The outcome was that Miss B's human rights and freedoms had been breached and that ventilation was to be removed, thus causing death.

These instances are, however, not necessarily the norm as yet, but produce narratives that have the potential to dispel many of the anxieties that exist around death, dying and control of the self. To a degree, the control of the self is attainable in the Netherlands, where euthanasia has been available since its inception in 2002 [44], but also in the retrieval of the *Ars Moriendi* as a means of engagement and the work of Carlo Leget [45]. Leget's work offers a more open framework in addressing the needs of the dying—offering spirituality, the potential for autonomy and the authority to decline interventions—but becomes constrained by the need to offer the work from a multi-disciplinary team approach contained within the biomedical discourse of clinical care. Such an approach may assist in engaging with equity in decision making with clinicians and having the confidence to take ownership for the natural path of dying and, as such, it disengages from the symbolically violent associations of prolonging life irrespective of life value. It allows the use of cultural and social capital to make choices that are necessary and, as such, produces a discourse of support for all involved. Gawande [29] also engages with the idea of the *Ars Moriendi* in that the artful death in contemporary societies does exist and can be attained through the use of hospice supports at this time, with some previously suggesting that the shift towards hospice care is de-institutionalising death and dying [46].

This idea, however, sits opposed to the 'letting go' ideology for which Gawande [29] advocates but is a viewpoint upheld by Farr Curlin, an American medical doctor, [47] who takes a bioethical overview

<sup>10</sup> Advanced care planning is "the process of thinking about, talking about and planning for health care and end-of-life" [39] (p. 1).

<sup>11</sup> MND is a progressive neurological condition that attacks the nerves in the brain and spinal cord.

of the art of dying. Despite Curlin [47] noting that not all deaths can be good, he continues to uphold the notion that “hospice and palliative medicine can best help patients engage in the tasks of dying well” (p. 14), with a biomedical disaster, beyond the current remit of medical practice, being the only way to move forward to achieve a new and artful death. Yet, despite these attempts to reconceptualise dying from being an over-medicalised life event, the notion that hospice has become the vehicle for change appears misplaced, as hospice remains a medicalised discourse of care at end-of-life. Hospice engages, at times, in practices that are not always aligned with the individual wishes of the dying, such as the routine use of clinical pathways for the dying, or the use of palliative sedation therapy. Despite suggestions that the clinician is no longer an overseer of the dying, but more of a guide sitting alongside patients and negotiating with them [48], we would argue that this clear transition from overseer to negotiator is too linear from a real-world perspective, as some clinicians remain reluctant to engage in meaningful negotiations that may detract from their authority and power.<sup>12</sup>

Furthermore, although it is known that “hospices specialize (sic) in the art of pain control” [49] (p. 7), and that there are those who consider that “nursing the dying is an art, as well as a science” [50] (p. 1), we contend that although Gawande [29] has some promising thoughts in relation to letting the dying die as they wish, he simultaneously contextualises his thoughts within the constraints of medical practices, evidenced in his thoughts about the hospice movement. This notion constrains his thoughts but may simultaneously offer an opening to engage with a new art of dying framework, and ultimately does little in reality to shift the dying from the current medicalised paradigm of care, whether hospital or hospice, which continues to be upheld by the current socio-political climate of rejecting the right-to-die bills presented to parliament.

## 7. Re-Presenting the *Ars Moriendi* as Individual Choice at End-of-Life

Dying is not predictable, nor is it containable despite the attempts of medicine to control this. It cannot be controlled or tamed; however, it can be managed but only in relation to the subjectivity of the individual involved. Medicine has attempted to manage the dying, thus, creating a situation whereby comfort is now produced through the “anatomy-clinical gaze” [5] (p. 179). Such manoeuvres produce a triumphant discourse through which medicine, with the support of law, control all but those who are capable of the individual suicide of the self [1].<sup>13</sup>

In considering, therefore, how the artful death needs to change in order to be relevant within the self-centric, individualistic societies of contemporary Western cultures, we have to look at how such values sit in relation to the dominant power of medical practitioners. Moreover, we have to consider what it is that is wanted in the twenty-first century that was less visible in previous eras, and that refers to the autonomy of choice over the demise of the self [1]. The idealised, medicalised and peaceful death is not a reality for many on this trajectory and, as narrated by Payne, “death is often a lot less serene than one might think. Death can be like life—a bit messy and awkward—some people die as they lived—‘at odds with the world’” [36] (p. 4) and, as such, “people’s fear of death has long been the ultimate instrument of power” [51] (p. 353), a situation that has become the focus of medical discourse in recent decades.

The medicalisation of dying, despite it visibly shrouding death with invisibility today, is not supported by all individuals and, as such, has led to the self-centric individual seeking rights over the death of the self. It has set in motion a campaign to allow the engagement of the self in decision making either at end-of-life or when experiencing intolerable suffering. Yet, through the expert power held by clinicians, together with the often-selective collaborative practices between medicine and law [1], the right to self-determination at this life stage remains elusive. Choice is all but an illusion in

<sup>12</sup> Pathways refer to specific practices through which medicine and law facilitate the ‘pathway’ to death; for example, the Liverpool Care Pathway, which has now been withdrawn from use in the UK [1].

<sup>13</sup> Both medicine and law reside within the construct and constraint of such governing bodies, through which mutually convenient collaboration occurs to ensure the compliance of the general population with the wishes of these institutions [1].



regard to individual wishes at end-of-life [1], and the re-presentation of the *Ars Moriendi*, suggested by Gawande, as a construct contextualised by, and contained within, the medical structure does not illuminate the pathway to improvements in end-of-life choices. We disagree that hospice provides the new art in dying and suggest that we take the idea of a contemporary *Ars Moriendi* to the socio-political debate and use it to facilitate the right to individual choice at end-of-life, whether that is a medicalised death or the right to assisted suicide in our death-denying culture.

More specifically, to date we suggest that those who have attempted to re-define the *Ars Moriendi* or consider it in a new light, have done so within the context of medical practice alone, with Curlin and Gawande being good examples of this. Unfortunately, this then appears to end up being just another version of the medical palliative care model of dying, thus offering a limited contribution to changing the face of end-of-life care choices. Drawing upon our professional palliative care experience in both the UK and NZ, the notion that hospice is the new *Ars Moriendi* is limited, as the work remains under the jurisdiction of medical professionals, with ‘enrolment into the programme’ a requirement. What is needed is the embracement of cultural diversity, perceptions, preferences and needs, many of which sit exterior to the boundaries of clinical practice; with the *Ars Moriendi* being a suggested starting point in redefining future end-of-life care that is not contained within, or constrained by medical authority, nor the socio-political debate currently present, but enhanced by the latter in terms of listening and taking forward-thinking actions. In trying to define a new framework for dying, with individuality being the central focus, it does not suggest that individuals will be isolated, but more that their choices will not be perceived as deviant but accepted within mainstream discourse in an open-minded format, with the possibility of social media presenting a means through which a new *Ars Moriendi* may be constructed and presented.

## 8. Conclusions

The art of dying, therefore, should no longer be prescriptive, and should be considered outside as well as inside the medical model of care. We must consider and treat the dying as true individuals who represent the lives led. Re-presenting the *Ars Moriendi* offers an opportunity for it to become a vehicle for medical, social, political and religious change and, if engaged with, provides a framework through which individual choice and equity in decision making may be achievable, giving us an image of how dying may appear in the future. This is not to say that medicine and their practices should be ignored or excluded, but clinicians, holistic practitioners, politicians and religious practitioners should work in cooperation to ensure the contemporary death is the one sought, and not necessarily the routinised one of prescription. This image of dying being located outside of the sphere of medical care, however, promises the possibility that we can take back our deaths in the future, but simultaneously means that death becomes an ordinary (if difficult) feature of our life course rather than a hidden extraordinary event. The contemporary art of dying in turn becomes a narrative for individual choice at end-of-life, thus enabling access to the subjective ‘good death’.

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