Responding to the proposal to legalise assisted suicide

To cure sometimes, to relieve often, and to comfort always  
Hippocrates

…And so each venture is a new beginning, a raid on the inarticulate  
TS Eliot

Healthcare ethics has been an evolving and dynamic part of medicine since ancient times. As well as covering basic principles such as the Hippocratic maxim of *primum non nocere* (first do no harm), it is increasingly clear that an important aspect of modern medical ethics is *primum non tacere* (first do not be silent). This has been particularly the case in terms of the silence or collusion of the medical profession at times of harmful practices engendered by contemporary widespread social pressure or enthusiasms, such as that of the German medical profession at the time of the T4 euthanasia programme in National Socialist Germany\textsuperscript{ii}, or the Swedish medical profession during the long period of forcible sterilisation of people with disability\textsuperscript{iii}.

Among the important roles of teaching healthcare ethics are those of developing an articulacy to tease out the complexities of the care of life with disability, challenging simplistic tropes, outlining the substantial body of work in clinical ethics, illuminating the challenge of recognising prejudices (such as those based on age, gender, race or disability) in public healthcare discourse, and reflecting on the challenges of contextualising concepts such as autonomy in terms of the aspects of existence such as that of our relational nature as human beings.

Formal teaching of healthcare ethics is relatively new in Ireland: I was involved in establishing the first interdisciplinary undergraduate course as recently as 2004\textsuperscript{iv}. Since this time there has been an increase in teaching at postgraduate and trainee levels, and the successive iterations of the ethical guidelines of the Medical Council represent a degree of sophistication and constant renewal unparalleled in other professional guidelines in Ireland.

Medical ethics represent a fusion between elements of philosophy and other aspects of the humanities allied to a vibrant sense of both the traditions but also the rapid evolution of the clinical sciences, best described in terms of care, communication and competence\textsuperscript{v}.
The proposal by Minister Halligan and others to join the minority of jurisdictions which have legalised assisted-suicide represents a point where it is important that we pause and reflect on what this means, what impulses draw some people to this concept, and what positive responses we can make to concerns and needs.

Two forms of suicide?
There have been major advances in promoting high-quality care at the end of life across the spectrum of healthcare provision in Ireland, and in particular through the provision of both palliative care services and increased training in palliative care across the professions. In addition, the professions have encouraged the development of advance care planning and provided assistance in ensuring that treatment at the end of life is proportionate to the goals of such advance healthcare plans.

One area of major concern in Ireland at end of life is that of suicide: suicide kills more people each year than road crashes, and is a source of grievous hurt to family, friends and those affected by the death. Much effort has been directed towards suicide prevention, and it is encouraging that the incidence of suicide has fallen from 13.5 to 9.7 per 100,000 between 2001 and 2015, albeit with persistently high rates among certain groups\textsuperscript{vi}.

That there might be two forms of suicide – one which is clearly upsetting and worthy of strenuous societal efforts to prevent, and one which might be tolerated and given the support and protection of law – is a deeply challenging and contradictory premise\textsuperscript{vii}. Simplistic tropes also haunt the discussion, with assumptions about psychiatric illness and irrationality.

The decriminalisation of suicide was a humane initiative, aimed at avoiding stigma and further hurt in terms of both completed suicide and attempted suicide, and emphasising the need for help and support for people in this situation, an impulse that holds true for those seeking assisted suicide as well. It was certainly never seen to be an expression of a societal desire to extend access to suicide as a human right, or to position suicide as an act that equality legislation might facilitate.

An idealised vision of unlimited autonomy
One of the striking aspects of the arguments advanced by the proponents of assisted suicide is an emphasis of choice and control, reflecting an emphasis on autonomy disconnected from the relational nature of our nature reminiscent of the central concepts of the market place, neoliberalism and the writings of Ayn Rand.

As described in a recent Irish paper on end-of life care\textsuperscript{viii} operating solely from a primacy of choice logic negates the interdependencies in care relations and assumes that all patients are independent and autonomous, even at moments of high vulnerability; there is a danger that those in end-of-life care are framed as abstracted rational choosers, ignoring that they are relational, emotional, and embodied human beings.
Choice logic may also lead to the prioritization of performance and control over compassion and care xv, failing in the process to fully acknowledge the reality of bodily decline and the needs of caregivers.

This has evoked concerns in healthcare ethics of how autonomy is defined in relationship to other aspects of ethics and how it has emerged as a dominant trope in ethics: the leading philosopher (and Chair of the UK Equality and Human Rights Commission until 2016) Onora O’Neill has proposed that ideally practice has to be developed within an ethical theory that does not impose an idealised picture of unlimited autonomy but allows for the variable and partial character of actual human autonomy x. This has been further developed by ethicists Pellegrino and Thomasma as the concept of the physician as moderate autonomist and moderate welfarist xvi.

In this healthcare has moved far from a previous stance of paternalism towards one which situates autonomy within a matrix most often expressed as a dynamic between the four pillars of beneficence, non-maleficence, autonomy and justice. Attaining this balance requires insight into the factors and practices that underpin these attributes, including a sensitivity to the potency of prejudice against ageing and disability.

**Prejudice against ageing and disability**  
In terms of ageing, a recent paper described how younger older people harbour prejudices against their own future ageing: asked about their opinion on living to the age of 100, this in their 90’s were broadly welcoming, while those in their 70’s showed marked ambivalence xiii.

Prejudice against disability is equally prevalent, and it is not surprising that all major UK advocacy groups for disability have rejected assisted suicide xiii.

Where there is legislation for assisted suicide it is often claimed that there is no evidence that the existence of legislation has led to significant harms for those with disability, but such studies have rarely looked at perceptions of illness, nihilism or ageism, all of which can be affected and influence care policies. For example, in societies where a negative public discourse related to living with dementia is tolerated, despite evidence of maintained quality of life for those so affected, assisted suicide may undermine the collective will to improve services and supports for those living with dementia xiv.

This was described with considerable impact by Susan Sontag in her Illness as Metaphor when she wrote “Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. ..It is impossible to take up residence unprejudiced by the lurid metaphors with this it is landscaped”.

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It is also a matter of concern that there are deep misperceptions about current medical practice: for example, a documentary on the matter broadcast on RTE Radio 1 in October 2017 proposed a rationale for assisted suicide in part on the basis that tube feeding would be used in a condition with a progressive dementia\textsuperscript{xv}, a course of action rarely if ever followed in clinical practice.

These concerns are mirrored in recent paper showing that for psychiatric patients who seek assisted suicide, symptoms of unbearable suffering may start at an early age and may further progress because of insufficient and/or poor patient-physician communication and inefficient treatment practices. Moreover, financial issues are also relevant – for example, low income necessitating careful consideration to determine whether alternative stays and treatments are feasible\textsuperscript{xvi}.

**More sophisticated conceptualisation of dignity**

Some of the advocates of assisted suicide use the phrase of ‘death with dignity: its proponents perceive dignity as being undermined by disability and suffering. Because the concept of human dignity carries strong rhetorical and moral force, we are obliged to examine any claims that our society is failing to act in accordance with it. Human dignity is not a thing that can be lost through disability, disease, dependency, or suffering, although insensitive treatment or attitudes to those so affected can constitute undignified care. It is important that the healthcare professions promote a critical debate on the complexities of discourse relating to dignity, and maintain care philosophies and routines that promote dignified care. Practical research on the topic points to elements including listening, communication, information, symptom control, facilitating daily living and including patients in decision-making: additionally, nurses' perceptiveness towards the patients is a core approach\textsuperscript{xvii}.

**Responding to concerns for future care**

It would appear that much of the impetus for seeking assisted suicide relates to a complex web of issues, including existential concerns over the future, fears that one’s voice will not be heard, misperceptions of care paradigms, occult (and sometimes overt) prejudice against disability and age, denial of the resilience of the human spirit in the face of adversity, and a failure to contextualise autonomy as one component of our relational framework of care and support through life. Public and private discussion with regard to assisted suicide should be seen to represent concerns over adequacy of treatment and support as well as existential concerns relating to the future: these need to be proactively addressed.

To ask doctors to run counter to this by killing patients short-circuits and undermines our impetus to care, comfort and support and damages our framework of care. Current and future patients need to be reassured that the response of the healthcare professions to distress and pain is one of compassion and care, addressing the needs at a range of levels - biological, psychological, social and spiritual - while respecting wishes to the greatest extent possible.
They should be reassured by not only the evidence that death is widely experienced as occurring with dignity within current paradigms, but also by the existing and ongoing development of care paradigms, training and research to continually enlarge the framework within which the final period of our lives is spent.

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