Dying for Choice: A Nurses Role in a New Ars Moriendi to Achieve a Contemporary Good Death

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In writing The socio-political debate of dying today in the United Kingdom and New Zealand: ‘leaving go’ of the biomedical model of care in order to develop a contemporary Ars Moriendi (Winnington, Holroyd & Zambas, 2018), the intent was to highlight that although the right to choice and the right to die debates are presently hot topics across many Western countries, they remain contained simultaneously within and constrained by medical and legal practices. The debate around choice and how we can move forward to achieve a contemporarily acceptable good death have, on a number of occasions, been proposed using the Ars Moriendi as a framework for change. Such approaches, however, are most often offered through a medical lens, and can be seen in the works of Far Currin (2015) and Atul Gawande (2014, 2010). Although these postulations are offered with good intent, and certainly bring the matter to the fore, they simultaneously hold on to the belief that a medical worldview alone is sufficient to meet the contemporary model of dying. While some of this literature is certainly helpful in highlighting the current discontent with death and dying for some individuals in Western societies, it does not eliminate the fact that little has changed for those seeking control over how they will die.

In raising the potential for a new and inclusive framework for dying we, as the authors of the above paper and as nursing professionals, are highlighting the experiences of some patients who have been caught up in the tangled web of collaborative medico-legal practices which have, on most occasions, resulted in the loss of control over their death. It is not surprising that such outcomes occur given the power that medicine and law have over our lives and ultimately our deaths. There is, however, an opportunity here for the nursing profession to take true ownership of their role as patient advocate to support those in our care whose preferences do not always align with contemporary medical discourse and, indeed, sit on the periphery of such practices. On a simplistic level, this may just be a case of ensuring that medicine and clinicians of all health disciplines avoid the trap of labeling individuals who have such ideas as being non-compliant, deviant or other; as this can be a default option when we are busy and time pressured. Such an approach suggests a closed framework of care being practiced.

Our discomfort with choices that are not medicalised is an issue that we, as clinicians, must acknowledge as being our problem, and not simply label those seeking alternative interventions is non-compliant. There has never been a more crucial time for nurses to advocate for the rights of those entrusted to their care while simultaneously encouraging medical and legal colleagues to move away from the rigidly constructed ideals of what dying should look like today; as we demonstrated in the cases of both David Nicholl and Emma Young from our original paper (Winnington et al, 2018). The patient voice must be heard if change is to occur to meet the requirement and attributes for a contemporary Western good death. Nurses are best placed to support this desire, even if we too have a discomfort with the changes being sought today.

Understanding and addressing such discomforts can be considered an ideal starting point from which change can occur. The problem is, however, that as nurses we too can be caught up in the medicalization of death and dying. Nurses often consider themselves as being holistic practitioners. The reality, however, is that clinical tasks often override the notion of ‘touch, talk, time’ and, as such, erodes the importance of nursing being a tactile profession (Molasiotis, 2018). More specifically, there is an apparent comfort for nurses in being able to speak the language of doctors, to be equals in clinical practice, with the reciting of pharmacological interventions being a clear example of this, particularly in palliative care. It is, therefore, our contemplation, understanding and implementation of what true holistic practice is that is at the root of the problem. Despite our intentions to practice with this model of care, it fails to be delivered when we reject interventions that suggest ‘otherness’, when they fall outside our scope of practice or field of knowledge. This is seen when individuals encounter difficulties if they seek to use alternative or integrated therapies in place of, or even alongside, Western medicine (Molasiotis, 2018). When this scenario is considered in terms of solely a therapeutic option and not specifically around choices when dying, this is clearly problematic, as one means of treatment will not suit all individuals. If, however, we contemplate this discomfort of medical and nursing professionals and shine that medical gaze (Foucault, 1973) onto the contemporary dying individual, we can see clearly how individual wishes are often
considered as deviant, odd or other, yet in reality they are merely preferences for their palliative care.

With the medicalization of many aspects of human life bringing numerous positive benefits, reduction in disease burden, improved morbidity and mortality across the life course for example, modern medicine can be commended for the gains achieved; yet death is different. Death is death. We stop existing as we currently experience life. Dying is a transitional process from the known to the unknown, and so poses profound discomfort in our need for order. For once, we cannot predict what lies ahead once the cessation of current existence has occurred, but the ownership of how this should happen must sit with the individual in question. As nurses, we must trust individuals to make rational decisions about death and not think them incapable of knowing how they want to die. Nurses, therefore, need to put aside the notion that otherness is problematic and support individuals whose contemporary take on achieving their own good death does not align perfectly with the current socio-medicalised death. In advocating for this change, nurses can help to actualize self-determination for the dying.

In considering these issues in the context of re-framing the Ars Moriendi to support the dying in contemporary society, it becomes evident how the freedom of lives lived are reflected in the choices made. This is best reflected in the growing momentum of desire to take back the ownership of one’s own body from the medical gaze, and seek independence in how death will play out. In postulating the notion of a new framework for dying today, which is open and individualized, where individual’s decisions no longer sit on the periphery of the currently acceptable medicalised death, it is clear that nurses are well placed to facilitate the inception of choice for those in their care.

This is not to suggest that nurses support assisted suicide, nor participate in such acts, rather they act as a committed advocate for individual choice and not get caught in the net that only a medicalised death is a good death. Given that a good death is one that most individuals want and seek; it is not for us to decide what this should look like, with a one size fits all prescriptive practice. With medicine currently dominating the landscape of the contemporary Western death, nurses have a key role to play in being entrusted by the individuals in our care to die as they have lived, through choices made.

References