Law, ethics and end-of-life care:
The policy and practice interface in England

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Introduction

Palliative care aims neither to hasten nor postpone death but instead offers support to people with advancing, incurable somatic illness (WHO, 2002). At the same time, individual nurses hold a wide range of views on euthanasia and end-of-life care, whilst the care-giving in clinical practice occurs in a social context in accordance with local and national policy (Quaghebeur *et al* 2009). Policy and practice must conform to the law, which defines liability in the end-of-life phase. However, as this paper highlights, the law has primarily focused on the criminalisation of euthanasia and less on the complex issues involved in the 'good death' concept. As a result, contemporary policy that helps to shape and direct end-of-life care faces a tension between end-of-life liability and the way in which palliative care is developing (LACDP, 2014).

The authors of this paper are not suggesting as a response to this tension that euthanasia should be legalised nor equating it with a 'good death'. The central argument from the authors of this paper is different: that for end-of-life care to develop and progress, practice has to interface with law and policy to a greater extent. A better interface will facilitate policy and law to be shaped by the complexity and demands of practice decision-making, so allowing a better understanding of what the end-of-life process entails. This is not to suggest that all end-of-life issues should be driven singularly by palliative care practice, but that a better future for the end-of-life entails the linking of law, policy and practice. Palliative care nurses have an obvious interest in the processes aimed at improving the interface between law, ethics and public policy. The approach of this paper is significant at the current time when palliative care policy is being actively debated (LACDP, 2014; NCPC, 2014, NICE 2015) with issues of communication between end-of-life care staff and patients as central (PHSO 2015; RCP, 2016).

Euthanasia: the prevalence of criminalisation and its aims

The legal landscape regulating conducts, which lead or may lead to the termination of a patient's life, is patchy. In 1993, in *Bland*, the House of Lords held that it was lawful for doctors to stop tube-feeding a patient in a "persistent vegetative state" if the continuation of feeding was not in the patient's "best interests". Recently, the *Bland* judgment was extended to patients of a minimally conscious state. Also, in 1957, in *Adams* it was held that the hastening of death, which occurs or might occur as a result of the administration of pain relieving drugs, is lawful under the doctrine of double effect. Furthermore, the law recognises the right to refuse treatment by a patient, regardless of whether this decision leads to the end of life. However, a competent patient cannot request any assistance in the termination of his/her life and as such the right to choose to die is not recognised. Hence, a person responding to such a request that causes the patient's death or who assists with his/her life termination is liable either for murder in the former instance, or for assisting suicide in the latter under s. 2 *Suicide Act 1961*. Arguably, such cases would fall within the *taking-of-life* scope and are therefore criminalised as euthanasia conducts. The arising legal question is why situations such as *Bland* (or even *Adams*) do not constitute cases of *taking-of-life* and are therefore not euthanasia cases. The point is that there is neither a persuasive nor otherwise coherent legal explanation for this difference in classification. Indeed, the appeal to the doctrine of double effect is characterised as a "most controversial legal issue with respect to palliative care" (Jost 2003). The situation is further confused because there is no legal definition of euthanasia. It appears, therefore, that whatever is intuitively regarded as euthanasia is criminally prohibited. Hence it has become a blanket term describing a multiple group of interrelated concerns. Recently, Keir Starmer MP, formerly Head of the UK Crown Prosecution Service, indicated that "a factor making it more likely that someone will be prosecuted is that they are a doctor or a health professional assisting someone" (HC 2015:Column 673). Starmer's observation echoes what Williams, a criminal law scholar, stated thirty years ago, that the law does not "leave the issue in the hands of doctors; it treats euthanasia as murder" (1983).

Arguably, it is indeed the criminal prohibition which has dominantly influenced the public meaning of euthanasia and not cases, such as *Bland* or *Adams*, which decriminalised healthcare interventions that lead or may lead to the termination of life. Notably, both the *Bland* best interest test and the *Adams* legitimisation of the doctrine of double effect operate in the form of case law ('court law'), and have not received a statutory law form (Montgomery *et al.* 2014). This has meant their implications have not been sufficiently debated and they remain familiar only within the healthcare context. In the public sphere, what prevails is the memory of the unwillingness of successive governments to legitimise the right to die for competent seriously ill patients. The avoidance of addressing these issues in UK Parliament has set a blanket prohibition as the definer of the formal public meaning of euthanasia.

This direction signifies the primary interest in the protection of the sanctity of life, (Norrie 2011), and especially the protection of the ‘vulnerable or immature’ (du Bois-Pedain 2003). Indeed, law and policy concerns have been defined by the ‘slippery slope’ fear and related nightmare of the development of an interplay between euthanasia and authoritarian policy choices (Freeman 1999; Keown 2002). The argument is that if we compromise the principle of the sanctity of life for the sake of people with a terminal illness or those who are physically paralyzed, we risk the emergence of “various dangerous possibilities” for other groups where “their quality of life might be regarded as diminished, such as the long-term depressed, the mentally and physically handicapped” (Norrie 2011). As Norrie claims, “a society with a population that is ageing and impoverished might be inclined to convert the permissive ‘can’ into the persuasive ‘ought’ (and then the required ‘should’?)” (2011). The policy of blanket criminalisation therefore aims at preventing the emergence of any social, policy or professional culture, which will transform those fears into reality. Certainly, there is a strong moral foundation which underpins this blanket policy. Nevertheless, the blanket nature of the criminalisation also carries significant problems, such as the simplification of a number of issues relevant to end-of-life processes.

The moral impact of criminalisation

Blanket criminalisation along with the predominantly negative perceptions of euthanasia have colonised the public understanding of the end-of-life phase and disassociated it from the complexity, the pragmatism, and the positivity which the palliative understanding of ‘good death’ embodies. Hence, the palliative understanding of ‘good death’ remains foreign to public discourse. Selected examples can demonstrate how the criminalisation of the (legally non-defined) concept euthanasia has created a vague moral context, which overwhelms the questions, issues and needs of the end-of-life process.

The moral impact of blanket criminalisation can be seen in the shaping of the semantics communicating the meaning of ‘good death’. The public use of the concept of ‘good death’ seems to be expressed in galvanised language, which provides only galvanised meanings of the end-of-life process. This is partially evident in the ‘End-of-life Care Strategy’, where authors’ describe a ‘good death’ in terms of the person dying being treated as “an individual with dignity and respect, in familiar surroundings, and in the company of close family or friends, and not being in pain or experiencing other distressing symptoms” (DH 2008). This perception is in line with ‘good death’ thoughts and feelings (which include dignity) and reference to being ‘made comfortable’ associated with an ability to relieve pain (Paddy 2011). However, in this way the policy document builds a public picture of tranquillity, which moderates different beliefs, experiences and understandings of the often difficult end-of-life phase. Moreover, this definition fails to accommodate the concerns over ‘letting go’, which is increasingly becoming an issue as medical technology advances. The reality commonly experienced by healthcare professionals is that death can be far from tranquil (PHSO 2015) and the picture of tranquility simplifies the ‘complex’ needs of this critical phase. Nevertheless, despite its simplicity, the representation of ‘good death’ as a phase of tranquillity is inevitably the only type of public language which can be at ease with the strong moral sentiments of blanket criminalisation.

The difficulty in choosing the appropriate policy language became evident in the debate of the Palliative Care Bill, which was introduced (unsuccessfully) by Caroline Spelman MP (HC 2009); where what might constitute a ‘good death’ was also debated. In her introductory speech, (HC 2009: Column 508), Spelman clearly disassociated the choice of *when* to die from the concept of ‘good death’ and asked the members of parliament to avoid any reference to this question. This can be seen as a call for silence on a significant end-of-life issue in a debate on end-of-life policy and practice, during which Spellman (ironically) indicated to parliament members the need for ‘talking about death’ as *the* significant issue. Hence Spelman’s anxiety, as a public person, to disassociate ‘good death’ from the controversy which surrounds the complexity of the choice of when to die (an issue which is morally influenced by the criminalisation of euthanasia), was apparent.

The moral impact of criminalisation and the anxiety that it can cause within the policy context when issues of ‘good death’ have been involved, can be evidenced in the fate of the Liverpool Care Pathway for the Dying (LCP); a case relevant to the policy theories of ‘moral panic’ (Payne 2015). ‘Moral panic’ can be defined as the widespread ‘concern’ that a “threat exists, is serious and that ‘something should be done’”. Importantly, the “concern is not directly proportionate to objective harm”, and is also characterised by ‘volatility’. The mass media play a critical role in the fast development of a widespread concern. (Cohen, 2002: xxvi). Usually, ‘moral panics’ and the related “concerns may lead to the labelling and stigmatising” of certain practices and “may precipitate harsh and disproportionate legislation”

(Cree, Clapton & Smith 2015). Arguably, due to the moral effect of the blanket criminalisation, the story of the LCP's collapse embodies those defining elements.

The LCP was recognised both nationally and internationally as a template to guide and enhance the care health professionals provided at the end-of-life for patients, relatives and carers. The policy aim was to transfer the gold standard of care provided by hospices to hospitals and community for those diagnosed as dying (Ellershaw & Wilkinson 2003). However, critical press reports threw a shadow over its use due to misguided perceptions of its application (Wrigley 2015). The LCP was inaccurately portrayed as a non-caring bureaucratic tool which was used to hasten death of patients placed upon it, although this was not in any way its intention (Wrigley 2015). Importantly, the moral connotations, communicated by the blanket criminalisation of euthanasia, functioned as fertile ground for the growth of a 'moral panic'; namely, a widespread 'concern', otherwise anxiety, within the policy context about the public legitimisation of the LCP use. The fast-developed 'moral panic' led to the independent Neuberger review of the LCP "More Care, Less Pathway" (DH 2013). Subsequently, the LCP, which was previously regarded as a recognised 'good death' policy framework, was phased out. The policy context payed less attention to the contribution of the LCP to the end-of-life process than to moral concerns surrounding the criminalisation of euthanasia.

The practice interfacing with law and policy: Complexity *versus* simplicity

The current health policy context was strongly influenced by the vision presented in the *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life* (Department of Health, 2008). It emphasised the need for high quality palliative care to enable a 'good death' in all care settings irrespective of diagnosis. It outlined the need for accurate data about end of life care, promoted clear clinical guidelines and the need to raise awareness about end of life care in the general population. However it did not focus on the requirement for a legal framework to palliative care practice.

Indeed with respect to end-of-life care, the public interface between law, policy and practice has primarily been defined by the simplicity *versus* complexity conflict. The policy language of tranquility (and the arising policy anxiety when there appears a deviation from moral certainties) both reflect the underpinning existence of a *simplified* end-of-life public policy framework. As the previous examples demonstrate, the framework is founded in the premises of blanket criminalisation. Within this framework, the complexity involved in 'good death' practice isn't apparent. When professionals become involved with interventions, the timing of death is moved away from its natural progression and moral dilemmas subsequently arise. If interventions were withdrawn, for example, the removal of intravenous fluids, to enable a person's body to 'naturally' die then this decision can be interpreted as being detrimental just because a perceived treatment is seen to be withdrawn. However, if intravenous fluids were maintained, death could be viewed as 'prolonged'; creating a time which is difficult for all concerned by predisposing the patient to distressing symptoms (Raijmakers *et al.* 2011). Undoubtedly, the introduction/withdrawal of interventions constitutes a complex process which arguably can remove 'natural' death from clinical settings (Oehmichen & Meissner 2000) and can create an aura of doubt in relation to achieving a 'good death'. Therefore, the crucial point arising from such considerations is that the complexity of these decisions requires a deeper understanding of what legal and ethical issues are involved.

However, the blanket criminalisation of euthanasia and its moral foundations still opt for moral simplicity and public policy certainty in relation to end-of-life questions. Inevitably, current law and policy rhetoric cannot accommodate the complexity which is inherent in the end-of-life process and in the development of 'good death' practice. The existing narrow framework can only increase the uncertainty surrounding professional dilemmas and it has been seen as unable to provide "realistic guidance for doctors"[20] and healthcare staff in general.

Examples of practice informing law and policy

Notwithstanding the blanket criminalisation, the courts have been prepared to recognise at least some of the complexity surrounding the end-of-life process and demonstrated a relevant creative inclination (du Bois-Pedain 2013). The doctrine of double effect, which can be applied to the administration of pain relieving drugs and the concomitant hastening of death, "made its first appearance at common law" in the 1957 murder trial of Dr Adams (Ost 2005); a controversial and "unusual" trial (Devlin 1986). Dr Adams was accused of intending to kill his patient by the administration of pain relieving drugs (*R v Adams)*. The most significant feature of the trial was that the prosecution charge of murder was interfaced with the end-of-life reality: “Even if Dr Adams was forced to admit that he knew that the doses were large enough to kill, the [prosecution] still [had] to tackle his plea that all he was doing was ‘easing the passing’ in a case of an inevitable death” (Devlin 1986). The trial was dominated by the perceptions of those health professionals who appeared as witnesses, turning a murder trial into an “interesting medical talk” (Devlin 1986). The trial was also influenced by the medical profession’s concern with “the possibility of a verdict which would put a doctor who failed to prolong life in peril of a murder trial” (Devlin 1986). Therefore, the birth of the legal understanding of the doctrine of double of effect took place within a context which dealt with complex professional meanings and concerns. As it was held that a doctor may do “all that is proper and necessary to relieve pain… even if the measure … may incidentally shorten life” (*R v Adams)*; its outcome challenged the dominant understanding of euthanasia (Norrie 2011). The court context successfully accommodated the requirement of a deeper understanding of complex healthcare decisions. Foremost, this ‘alternative evaluation of law’ represented an attempt to inform legal definitions with a practice perspective.

The most remarkable judicial decision which accommodated the controversies of end-of-life process was, undoubtedly, the judgment in *Bland*. *Bland* was a landmark case, as it implied that passive euthanasia could be lawful even though there had been no legislative change in the law of murder. Notwithstanding the significance of this development, *Bland* importantly also brought palliative care issues into the forefront of policy thinking by requesting that “the moral, social and legal issues of the present case should be considered in Parliament” (HL 1994). As a response, the Select Committee on Medical Ethics produced a report which dealt with the euthanasia issues (HL 1994). The Committee concluded that there was not sufficient reason “to weaken society's prohibition of intentional killing which is the cornerstone of law and of social relationships” (HL 1994). Crucially, the committee also ‘welcomed’ the achievements in the field of palliative care, and called the Government to provide more resources.

Bland and the subsequent report occurred at a transitional time for palliative care services and brought palliative care to policy attention. Prior to 1990, the growth of palliative care had been due to the galvanising effect of a “bottom up” vision, leading to a sustained, rapid expansion of voluntary, locally-managed, hospice units and community services (Clark 2007; Wood J. & Clark D. 2008). The early 1990s began a period of maturation and re-integration into mainstream care. The following period was associated with a gradual strengthening of the links between the palliative care voluntary community and the NHS bureaucracy (Hockley 2008). This integration has been associated with increased national social policy, evidence based practice guidelines and funding. Arguably, throughout those years, the channelling of professional experiences to the policy context constituted the most significant end-of-life care development. The 2008 *End-of-life Care Strategy* constituted a significant policy step, as it accommodated, disseminated, and promoted ideas which emerged within local professional establishments; such as the exemplary case of the LCP which, as the *End-of-life Care Strategy* indicated, had been developed by specialist palliative care teams (DH 2008). Four years later, the *End-of-life Care Strategy: Fourth Annual Report*, which reported on the "progress in delivering the strategy", indicated the success of the LCP with "over 2,000 organisations in the UK" being "registered with the LCP central team, including hospitals, hospices, care homes and home teams" (DH 2012).

Perhaps the post-*Bland* period should be seen as period of greater understanding of what end-of-life care *is* about, and even more of what 'good death' *is* about. The remark of Stephen O'Brien MP during the debate of the privately introduced Palliative Care Bill in 2009 is rather characteristic:

> "...'a good death'. I dare say that if we track back only a few years, we as politicians would have been extremely chary about using that sort of phrase in the public domain. People recoiled from that slightly. It is a remarkable sign of how much we have come to understand the issues that surround this important matter" (HC 2009: Column 516).

Arguably, the undercurrent trend of linking emergent practice lessons with the policy context should be seen as the significant event of this period.

Cooperation: Practice, Policy and the Law

Several times, members of UK parliament have unsuccessfully tried to introduce legislation to decriminalise assisted dying. In 2015, Lord Falconer's *Assisted Dying Bill* was debated, also unsuccessfully. The Government did not take any positional stance, and allowed "MPs a free vote" (Bingham & Kirkup 2014). During the parliamentary debate, 29 speakers mentioned the word ‘palliative’ 70 times and demonstrated the conceptual tension between blanket criminalisation, the right to die and palliative aims (HC 2015).

There are tantalising issues which need cooperation rather than conflict between practice, policy, and the law. For example, the doctrine of double effect seems to function as an unsatisfactory legal solution to the palliative practice needs (Biggs 2001). Additionally, there is a need to explore the doctrine under arising new evidence that pain killing drugs, properly used, need not hasten death potentially (Thorns & Sykes 2000). Continuous deep sedation also constitutes a controversial issue within end-of-life care. Studies showed that “deaths in UK are particularly likely to involve continuous deep sedation” and this could be interpreted as a case of ‘slow euthanasia’ (Seale 2009). Seale (2009) claims that “a better understanding of the context in which these decisions are taken is needed to assess this”; namely, a need for law to be informed by practice complexity. The emerging trends discussed earlier demonstrate the value of this process, which can be a two-way process that also benefits practice when well-informed appropriate training is provided. Professionals also need to understand the scope of their practice and avoid practice-routinisation (NICE 2011). For example, by the very nature of their diagnosis, a person with a life-limiting condition may be perceived as vulnerable, particularly if there are additional health needs, (learning disability or dementia, etc.), which may compound professionals’ understanding of treatment options. Training around vulnerable adults could support professionals with an appreciation of the meaning and implications of vulnerability.

Even more importantly, ‘good death’ needs to develop beyond the mere interface between euthanasia and palliative care. End-of-life processes should become more open to social policy questions. For example, the dying person’s preference for setting the stage for their own death is not always straightforward. Since the development of palliative care, there has been a slow but long-term shift in the place of death away from the home towards institutions (Gomes *et al.* 2013), which has been partly reversed in recent times, (ONS 2012), but still dominates. This risks the sequestration of patients who experience “dirty dying” away from the time and place in which they had imagined a ‘good death’ (Lawton 1998). It has long been considered that ‘home is best’ and more ‘natural’ to a ‘good death’ by offering greater autonomy to the patient (Thomas *et al.* 2004). However, people’s preference for dying at home may change with proximity to death, often because the degenerative nature of the body in death becomes progressively more difficult to manage (Thomas *et al.* 2004). These are questions which demand social policy research initiatives, and they cannot be handled singularly by professionals. A better future of the end-of-life phase entails the linking of policy and practice, but also the law's awareness of this need.

Conclusion

This paper has argued that public policy should be less influenced by the legal preoccupation with criminalisation and euthanasia and more focused on practice concerns that allow a full range of considerations as to what might constitute a 'good death'. For end-of-life care to develop and progress, practice has to interface with law and policy to a much greater extent. Cooperation and dialogue between the three areas of practice, policy and law will allow a better understanding of what the end-of-life process entails and hence to allow room within policy and law to be shaped by the complexity and demands of practice decision-making. The needs of patients, families, and society more generally are all bound up within the concept of a good death, but in order to achieve this goal of end-of-life care we need the full integration of policy, law and practice initiatives.

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