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Transatlantic Issues: Report from Scotland

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Transatlantic Issues: Report from Scotland

Introduction

Several bioethical topics received a great deal of news coverage here in Scotland in 2009. Three important issues with transatlantic connections are the swine flu outbreak, which was handled very differently in Scotland, England and America; the US debate over healthcare reform, which drew the British NHS into the controversy; and the release to Libya of the Lockerbie bomber, which at first glance might not seem particularly bioethical, but which actually hinged on the very public discussion of the prisoner's medical records. On a national level, there have been attempts in both Scotland and England to change the law on assisted suicide, where success looks more likely than ever. This paper will discuss each of these issues, and hopefully raise awareness of how these issues were dealt with in the UK and its component countries.

Swine flu

The spread of the H1N1 flu strain from Mexico around the world was one of the biggest news stories of 2009. The initial fear that mortality rates would be very high was not borne out by reality, and at the time of writing we are awaiting the second wave of swine flu brought by autumn and winter, which looks like being less severe than the first wave, contrary to expectations.¹ But the differing responses of the National Health Service in England (and Wales) and NHS Scotland provide an interesting contrast. Given that many foreigners have trouble distinguishing between the UK and Scotland, and the frequent references in international media to Scots as

English or British, it might come as a surprise to many that Scotland has its own devolved government, which has responsibility for several policy areas, one of which is health. NHS Scotland is entirely autonomous and rather more centralised than NHS services in England and Wales.

Initially, Scotland was proportionally worse hit by swine flu than England, with a high concentration of cases in Glasgow and the surrounding area; at one point in June England, which has 11 times the population of Scotland, had “just 2.6 times the level of swine flu”. Several Scottish schools were closed in order to protect children when pupils contracted swine flu, but children were generally not given Tamiflu prophylactically, unlike in England where those in the same class as infected children were given the drug even if they had shown no symptoms.

Perhaps the English government’s reaction to swine flu was dictated by the media, who pounced on the story and produced numerous helpful headlines like “UK’s swine flu death toll doubles over three days”² (from 7 to 14) – hardly the stuff of nightmares. Such headlines persist: the Sunday Times recently ran a story stating that people might have to hold funerals at home because of the sheer number of people dying. Even if the worst mortality predictions turned out to be correct, however, the maximum number of deaths in Scotland would be 2000 – presumably across several weeks, which would not stretch funeral services too much. By the time it became apparent that the mortality rate from swine flu is actually lower than that from normal seasonal flu, the damage was done: several hasty decisions by the powers that be had resulted in potentially negative consequences for the public.

First, many children in England were given Tamiflu prophylactically, despite there being little evidence that it works in this way. Preventing children from contracting swine flu is a laudable aim, but if the means is not proven and such large-scale dispensing increases the likelihood of viral resistance to Tamiflu emerging, it might well have been more prudent to save the Tamiflu for when it is really needed.

Second, it is also far from clear that Tamiflu should even have been given to children who were actually found to have contracted the virus but did not have underlying health conditions such as asthma. Research has shown that giving children Tamiflu does not prevent any of them from dying; it merely reduces the duration of their symptoms by one day and reduces severity of symptoms slightly. This would be fine if there were no side effects, but in fact nausea and nightmares were far from rare. As one expert put it, "The downside of the harms outweigh the one-day reduction in symptomatic benefits."³ And again, giving all children Tamiflu greatly increases the chance of a resistant strain of the virus developing. According to the World Health Organisation, the same is true of adults: "Healthy patients with uncomplicated illness need not be treated with antivirals".⁴

The fact that Tamiflu does not improve children's chances of survival leads on to the third point. Even before it was announced that swine flu had reached pandemic proportions (which itself scared the public further, as many people thought the move to pandemic meant increased risk of death rather than increased risk of infection) the UK Department of Health had announced that 132 million doses of the as-yet-uncreated vaccine against swine flu had been ordered – enough for two doses

for every man, woman and child in the UK (so Scotland is complicit here)⁵. This might have seemed like a good idea at the time, but there are two major problems with it. First, we don't try to vaccinate everyone against normal seasonal flu, despite its higher mortality rate. It seems likely that the Government's decision to buy enough for everyone was a product of the fact that when swine flu does kill, it kills a different demographic to that dispatched by normal flu – ie. the young and healthy rather than the elderly. If vaccination were not universal, the main cost would not be in lives but to the economy. The second major problem is that the trials of the vaccine that have now been conducted in Australia, the US and the UK suggest that one dose is perfectly sufficient to provide immunity to swine flu. Thus the government has ordered twice as much as is necessary, even if you accept that universal vaccination is a good idea (some patients such as children may require two shots, however).⁶ Of course, allowances must be made for the fact that it was not entirely clear at the time how deadly the virus is, but simply assuming that everyone would need to be vaccinated suggests that the motive was reassuring the public rather than clinical need.

The fourth (but probably not final) hasty idea to protect the public against swine flu was the National Flu Service and Hotline. As already stated, business in Scotland was pretty much unchanged: in England and Wales, 1500 medically unqualified call centre workers were recruited to take patients through a checklist in order to establish whether they (probably) had swine flu. A website was set up with the same function. In both cases, those who were judged to have flu were told how to get themselves some Tamiflu, which was otherwise a prescription-only drug. Quite apart

from the fact that misdiagnosis seems likely with such a system – and there have been allegations that symptoms of meningitis may have been incorrectly judged as being flu-related even in face-to-face consults⁷ – such a system allows members of the public to “play the system” and call back once they know how to answer in order to obtain Tamiflu. This does not seem like a well-thought out medical procedure. In Scotland, of course, patients still had to see a doctor to get Tamiflu; in fact, those calling NHS24, a general helpline, were told: "Most people with flu do not need to see a doctor, as flu is usually a self-limiting' infection. This means that the body normally fights off the infection without medical treatment. The symptoms of flu usually clear within 4-10 days."⁸ This seems a more prudent approach than that which was adopted in England. Even if a patient were to be seen by a doctor, most GPs would be unable to tell whether a case was regular flu or swine flu, and advising patients without underlying medical conditions to stay at home and wait it out seems preferable to prescribing Tamiflu to those who may not need it. (One other problem with the English set-up was that many patients who were diagnosed with swine flu had to then go to the pharmacy in person, putting others at risk, because relatives were not permitted to pick up the drug for them.)

Overall, while mistakes were made in Scotland too, the official response to swine flu in England appears to have been particularly hasty and badly thought through. The UK Department of Health seems to have attempted to adopt a “safety-first” approach, with the unfortunate result that the risk of harm was actually increased due to policy decisions taken without due regard for the evidence or consideration of the possible consequences.

US Healthcare and the NHS

Barack Obama's brave attempt to reform the US healthcare system had an unexpected transatlantic effect: opponents of his plans turned the NHS into a political hot topic by claiming that the President's proposals would result in a system very similar to that operated by the British National Health Service. This was rather surprising to observers in Scotland and the rest of the UK, who would generally tend to regard this as a compliment rather than a criticism. This was obviously not the intention of the vehement opponents of reform, who made some outrageous claims about the NHS, among them the infamous claim that the NHS operates fascist "death panels" that decide who will live and who will die, and that the NHS is a socialist system. The fact that the NHS is simultaneously accused of being socialist and fascist might give some idea of the coherence of these claims, but the latter claim is basically correct, despite the obvious reluctance of some Democrat politicians to admit it. The NHS was created in 1948 with three core founding principles: that it meet the needs of everyone, that it be free at the point of delivery, and that it be based on clinical need, not ability to pay.⁹ More recently, NHS Scotland has emphasised the importance not only of improving health but also of reducing health inequalities, which basically means that the health of people from deprived areas are targeted and schemes to help them may receive more funding – in a crude sense, taking from the rich to give to the poor. Given the extreme reaction in the US to even the vaguest hint of socialism, it seems likely that combating inequalities in this way is not a priority for the opponents of Obama's plans. New NHS core principles were added in 2000, the eighth of which relates to inequalities:

- The NHS will provide a comprehensive range of services
- The NHS will shape its services around the needs and preferences of individual patients, their families and their carers
- The NHS will respond to the different needs of different populations
- The NHS will work continuously to improve the quality of services and to minimise errors
- The NHS will support and value its staff
- Public funds for healthcare will be devoted solely to NHS patients
- The NHS will work with others to ensure a seamless service for patients
- The NHS will help to keep people healthy and work to reduce health inequalities
- The NHS will respect the confidentiality of individual patients and provide open access to information about services, treatment and performance

What of the “death panels” accusation? One of the many ironies of the predominantly Republican criticism of the reform proposals is that their criticisms of the NHS – a rigorously evidence-based organisation - lack the slightest evidence. The death panel accusation is based on a gross distortion of the role played by a key NHS body: NICE, the National Institute for Health and Clinical Excellence. (NICE does not operate in Scotland, but we have our own equivalent, the Scottish Medicines Consortium, which is independent but uses NICE’s evidence evaluations to make its own decisions.) NICE examines new medical appliances and drugs to see if they are cost-effective enough to be funded by the NHS, with the typical maximum cost per quality-adjusted life year (QALY) being around £30,000. It does this by examining all the available evidence on the effectiveness of the intervention in question. Sometimes it is decided that drugs are too expensive and cannot reasonably be funded: this in turn leads to negative media coverage claiming that people are dying

because of NICE's decisions. This last claim is not strictly true. Generally speaking, the drugs that NICE refuses to approve are those that will add only a few weeks or months to a terminally ill patient's life, at great expense (and NICE's decision means only that the patient will die sooner, it does not cause their death). Obviously it would be better for the patient if the drug he needed were funded, but the NHS has a finite budget and paying £100,000 for this patient to have a few more days of life might well mean that other patients elsewhere in the NHS die sooner.

In the hands of Sarah Palin, these facts were personalised into a situation where *each* patient must face a committee that will decide whether *each patient* is worth spending money on. This is exactly what NICE does not do: it does the very difficult job of looking at the wider picture, without personifying the debate. When the media begins to focus on individual cases, the results can be quite worrying. In the case of Herceptin, a breast cancer drug, the media-inspired public uproar at NICE's refusal to fund the drug led to the Minister for Health unilaterally declaring that it would be funded, despite the fact the NICE's normal criteria had not been met. Of course, pharmaceutical companies are quite happy for the debate to be personified, but a truly fair healthcare system – which is what the NHS aspires to be – must decide how best to spend limited resources. Those who are opposed to the job that NICE does would do well to ask themselves what the ceiling per QALY should be, if £30,000 is too low. Should NICE fund a treatment that will cost £1 million and give an old man an extra month of life? If not, then the only question is exactly where the line should be drawn. Another point that is often overlooked is that NHS patients can

still pay extra for private treatment if they want to – although “topping up” is regarded by some as unfair, it is really more unethical to deny people this option.¹⁰

Ultimately, the current American system is a lot more fascist than anything on this side of the Atlantic. Under the current system, most of the poor, weak and disadvantaged are simply left to die if they cannot afford. As already mentioned, in Scotland the worst-off receive more help from the healthcare system, whereas in America the opposite is true. Despite spending twice as much GDP on healthcare (17% to our 8%), the US ranks lower than Britain in international rankings.¹¹

Opponents of US healthcare reform would probably dismiss this as evidence that “death panels” are more efficient, but the fact is that the NHS is a model worthy of imitation.

The Bomber’s Confidentiality

The Lockerbie bombing was something of a jurisdictional jungle from the beginning. Pan American Airways Flight 103, carrying mainly US citizens, took off from England, exploded over Scotland and crashed into the village of Lockerbie, killing 243 passengers, 16 crew and 11 on the ground. Many years later, Abdelbaset Ali Mohmed Al Megrahi was tried under Scottish law in the Netherlands on an American base, convicted of mass murder and in 2002 was sentenced to life imprisonment in a Scottish prison. Megrahi always denied his involvement and continued to appeal against his conviction until he dropped his final appeal in 2009 in order to “smooth the way” for his compassionate release (which was not technically necessary, although it would have been for his release under the Prisoner Transfer Agreement

that exists between Britain and Libya, which was not granted). Since 1993 it has been possible for the Justice Secretary to release prisoners on compassionate grounds if they met certain criteria; no minister had refused such a request since 2000.¹² When the Scottish Justice Secretary announced that Megrahi was to be released, there was a variety of reactions, but condemnation from the USA was almost unanimous.

While some victims' families in the UK either had doubts about Megrahi's guilt or believed compassion was appropriate, the US reaction seems to have been predicated on certainty of guilt and strong belief in "eye for an eye" justice. (One American said that he couldn't have been given compassionate release if he'd been executed, which could be used to argue either side of the argument). In fact, despite MacKaskill's claim that compassion is part of Scottish identity (and his attempt to speak for the nation irritated many), 73% of Scots and 79% across the UK opposed Megrahi's release,¹³ which may have been motivated in part by the Scottish Government's desire to display its autonomy on the international stage.

Regardless of whether Megrahi should have been released, the interesting bioethical facet of the case is the prominence given to his medical records in the affair. Kenny MacAskill stated that Megrahi met the criteria for compassionate release because he had terminal prostate cancer. Normally such information would be confidential, but his lawyers had previously stated that he had the condition. Nevertheless, it is surprising that the Justice Secretary was so specific in his statement announcing Megrahi's release, stating that "Assessment by a range of specialists has reached the firm consensus that his disease is, after several different trials of treatment, "hormone resistant" - that is resistant to any treatment options

of known effectiveness.”¹⁴ It is unclear whether Megrahi actually consented to this very public disclosure of the gravity of his condition; if he did agree as a precondition to his release, it could well be argued that valid consent was not obtained.

In the aftermath of his release, the bomber’s medical status became a political hot potato in Scotland, and questions were asked about the accuracy of the diagnosis. Scottish Prison Service guidance states that release on compassionate grounds “may be considered where a prisoner is suffering from a terminal illness and death is likely to occur soon...there are no fixed time limits but life expectancy of less than three months may be considered an appropriate period”¹⁵, although the law itself states only that “The Secretary of State may at any time, if satisfied that there are compassionate grounds justifying the release of a person serving a sentence of imprisonment, release him on licence.”¹⁶ One Labour Member of the Scottish Parliament (MSP), Dr Richard Simpson, claimed that Megrahi might well live for more than three months and might well live for eight, and questioned the strength of the medical evidence for his release. (Labour is the main opposition party in Scotland, and the Justice Secretary is a member of the Scottish Nationalist government, so there may be something of a conflict of interest at play here.) Previous assessments in June and July had suggested Megrahi would live for up to 10 months. The *Scotsman* newspaper has claimed that none of the oncologists consulted about the prisoner’s condition “would be willing to say”¹⁷ whether he would live for less than three months. MacAskill has insisted that advice was sought from a range of specialists, but it appears that only the Prison Service GP was willing to state that Megrahi met the three-month criterion. One of the oncologists who

was consulted was Karol Sikora, who displayed unusual disregard for the patient's confidentiality in an exclusive interview with an English newspaper which ironically also stated that one of the other doctors involved refused to discuss the case because of confidentiality concerns.¹⁸ Sikora revealed that the expert medical evidence was paid for by the Libyan government, who also mentioned that 3 months was an important timescale to bear in mind.

It is unusual to say the least that a patient's medical condition should be so publically debated; an anonymous associate of the Justice secretary was quoted as saying "I really don't think we should be speculating on the day somebody is going to die", but given that a prediction of when Megrahi might die was a necessary criterion for his release, this is not a particularly helpful statement.¹⁹ It is certainly true, however, that it is unfortunate that the highly personal terminal diagnosis of a patient should be used to score political points – regardless of his guilt or innocence. Remarkably, if Megrahi should miraculously recover, he faces the prospect of his release being revoked: "consideration would be given to revocation of the licence and the prisoner's recall to custody"; unlikely though this is, his medical status nonetheless continues to dictate his judicial status.²⁰

Assisting Suicide

There has been increased debate about assisted dying in all component countries of the UK, but actual legal changes may soon be put to Parliament in Scotland, and the Director of Public Prosecutions for England and Wales recently issued new guidelines clarifying the law regarding assisted suicide. Suicide has been decriminalised (but not

technically legal) since the passing of the Suicide Act in 1961.²¹ However, assisted suicide remains an offence, punishable by up to 14 years' imprisonment; therefore, those who seek aid in dying are requesting their helpers to break the law. The same applies to euthanasia, which is identical in the eyes of the law to murder, regardless of any sympathetic motive of mercy killing or the presence of consent.²² In Scotland, while euthanasia would be treated in the same way as south of the border, there is no specific crime of assisting suicide, and if a prosecution were to take place it would probably be for culpable homicide.²³

Member of the Scottish Parliament (MSP) Margo MacDonald has obtained sufficient support from other MSPs for her End of Life Choices (Scotland) Bill to be considered by a parliamentary committee, a necessary step before her proposals can be put before the full parliament for a vote. MacDonald suffers from degenerative Parkinson's Disease, and thus has a very personal interest in people having the right to assisted dying should they so choose. The stated purpose of the Bill is "to clarify the laws in Scotland relating to the assistance given to end the life of a person requesting such help before death would occur naturally", but in effect it seeks to legislate against the prosecution for culpable homicide of those who provide assisted suicide: "the bill would propose that, on the request of the patient, and conditional on legal requirements being adhered to, a physician assisting a "patient" to die will not be guilty of an illegal act."²⁴ The consultation document for the bill which won the support of several MSPs also points out that doctors are already permitted by law to assist a patient to die via the withdrawal of life-sustaining treatment; indeed, it is against the law to grant any such request. It is proposed that the patient must

make two requests 15 days apart before they can be assisted, which some might regard as quite a long time for a patient to wait if he/she is suffering, but others will claim is not long enough. MacDonald's Bill would also not sanction euthanasia, which would leave those most at need of assistance – the extremely incapacitated – no better off.

Despite these reservations, MacDonald's Bill has widespread public support, with 83% of Scots supporting measures of this kind (against 71% in the rest of the UK).²⁵ However, it seems unlikely that it will become law in part because of the strong religious lobby in Scotland. Previous attempts by Jeremy Purvis MSP in Scotland and Lord Joffe in England to change the law faced orchestrated campaigns by church leaders against the proposed reforms, with the resultant accusation that they were wielding power disproportionate to the number of citizens they represented. There has been a similar reaction to MacDonald's proposed changes, with the Catholic Church in particular criticising the legislation. Archbishop Mario Conti has stated that the proposals would put doctors "virtually above or outside the law". As Paul Brownsey has pointed out, however, surgeons are the only people who can cut people and not be prosecuted, yet they are not regarded in this way; furthermore, one either acts within the law or does not; if the law permits doctors to assist in suicides, there is nothing 'virtual' about their legal status.²⁶

MacDonald states in the introduction to her consultation document: "For some people the question is irrelevant because they believe God determines when life

ends, and nothing that is proposed will compromise their belief. But our society embraces many people who do not share this belief, who believe in the autonomy of the individual in taking responsibility for, and exercising choice over how life is lived, including the end of life.”²⁷ Most people in Scotland seem to agree with these sentiments, despite the very vocal protests of a largely ecclesiastical minority.

In England, where assisted suicide is clearly illegal, there has been ambiguity for some time over exactly what penalty those who help their loved ones die would face. This issue has become particularly prominent in the media with the increasing regularity of Britons ending their lives at Dignitas, an assisted dying clinic in Switzerland. While someone who procured lethal pills for a dying relative clearly ran the risk of prosecution, despite the paucity of recent court cases, it was very unclear whether helping someone get to Switzerland constitutes assisting their suicide. (A related issue is that people seem to be committing suicide sooner than they wish because they have to at least be fit enough to get on a plane, whereas they could wait longer if assisted suicide were legal in England.) Debbie Purdy, who suffers from multiple sclerosis, successfully argued in the House of Lords that the Director of Public Prosecutions had an obligation to clarify the law in this regard. Keir Starmer, the man in question, recently issued his guidelines, which provide surprisingly detailed criteria for determining whether prosecution in a given case is in the public interest (see appendix).²⁸

Margo MacDonald was gratified by Purdy’s victory, but stated that “Other people in roughly their position cannot go to Switzerland because they don't have the money.

Only primary legislation can provide everyone with the same range of choices, and autonomy, should they find their lives to be intolerable.”²⁹ However, Starmer has specifically stated that the guideline apply to assisted suicide within the UK, as we couldn’t have one law for those who can afford to travel abroad and another for those who can’t. Despite his claim that the law has not changed, therefore, the new guidelines make it very clear under which circumstances prosecution is very unlikely, in effect decriminalising assisted suicide in England and Wales.

Conclusion

I hope to have illustrated in this brief report that things are often done differently in Scotland. While the entire UK was united in condemnation of the besmirching of the good name of the NHS in the American media, Scotland has marked itself as distinct from England and the rest of the UK in the three other areas discussed. Our reaction to swine flu was perhaps more prudent and ethical; our release of the Lockerbie bomber illustrated our governmental autonomy, despite the unfortunate public discussion of confidential information; and we look likely to adopt laws that are more compassionate to those who wish to end their lives. Scotland is fortunate to have enough autonomy to make such decisions; whether more such powers are needed is an ongoing debate.

Appendix: Factors affecting decision to prosecute for assisting suicide ²⁸

Factors in favour of prosecution (factors 1 to 8 carry more weight):

- The victim was under 18 years of age
- The victim's capacity to reach an informed decision was adversely affected by recognised mental illness or learning disability
- The victim did not have a clear, settled and informed wish to commit suicide
- The victim did not indicate unequivocally to the suspect that he or she wished to commit suicide
- The victim did not ask personally on his or her own initiative for the assistance of the suspect
- The victim did not have a terminal illness, incurable disability or severe degenerative physical condition
- The suspect was not wholly motivated by compassion
- The suspect persuaded, pressured or maliciously encouraged the victim to commit suicide
- The victim was physically able to undertake the act that constituted the assistance him or herself
- The suspect was not the spouse, partners or a close relative or close personal friend of the victim
- The suspect was unknown to the victim and assisted by providing specific information via, for example, a website or publication, to the victim to assist him or her
- The suspect gave assistance to more than one victim who were not known to each other
- The suspect was paid by the victim or those close to the victim for their assistance
- The suspect was paid to care for the victim in a care / nursing home environment
- The suspect was aware that the victim intended to commit suicide in a public place where it was reasonable to think that members of the public may be present
- The suspect was a member of an organisation or group, the principle purpose of which is to provide a physical environment in which to allow another to commit suicide

Factors against prosecution (factors 1 to 7 carry more weight):

- The victim had a clear, settled and informed wish to commit suicide
- The victim indicated unequivocally to the suspect that he or she wished to commit suicide
- The victim asked personally on his or her own initiative for the assistance of the suspect
- The victim has a terminal illness, incurable disability or severe degenerative physical condition
- The suspect was wholly motivated by compassion
- The suspect was the spouse, partners or a close relative or close personal friend of the victim
- The actions of the suspect, although sufficient to come within the definition of the offence, were of only minor assistance or influence
- The victim was physically unable to undertake the act that constituted the assistance him or herself
- The suspect had sought to dissuade the victim from taking the course of action which resulted in his or her suicide
- The victim had considered and pursued to a reasonable extent recognised treatment and care options
- The victim had previously attempted to commit suicide and was likely to try to do so again
- The actions of the suspect may be characterised as reluctant assistance in the face of a determined wish on the part of the victim to commit suicide
- The suspect fully assisted the police in their enquiries into the circumstances of the suicide or the attempt and his or her part in providing assistance

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